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# SELECTED PAPERS

# From

# PROFESSIONAL PROGRAM SEGMENTS

# Of

# UNITED CEREBRAL PALSY'S ANNUAL CONFERENCE

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
OFFICE OF EDUCATION

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HOUSTON, TEXAS
March 21-23, 1968

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# PREFACE

With the intense service and legislative activity in the field of cerebral palsy this year, it was appropriate to highlight three areas of emphasis at United Cerebral Palsy's Annual Conference -- the emerging role of government in the provision and support of community services for handicapped children and adults, the urgent need to upgrade the care of cerebral palsied persons in state institutions, and the developing role of architecture in service programming.

While it is not possible to reproduce all the material presented at the UCP Conference in Houston in March 1968, several key papers and discussions are included here as a part of our annual "Selected Conference Papers". Several point out the important role the well informed architect can play in designing facilities and equipment which can enhance the effectiveness of community services for handicapped children and adults.

The papers of Dr. Kugel, Mrs. Haynes and Miss Campbell give a clear insight into our responsibilities to see to it that the total daily management of individuals in state institutions can be vastly improved to give their lives dignity and purpose. I commend them for thoughtful reading. Behavior modification, a new name for operant conditioning, has important implications for better education and services for cerebral palsied children and Dr. Hinojosa's remarks summarize the current status of these developments.

Brewster S. Miller, M.D.
Medical Director
United Cerebral Palsy Associations, Inc.

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.
ANNUAL CONFERENCE
MARCH 21-23, 1968
RICE HOTEL
HOUSTON, TEXAS

Summary Conference Presentation:

# WHAT ARE OUR SERVICE NEEDS THAT REQUIRE ATTENTION IN ARCHITECTURAL PLANS -- REMOVING ARCHITECTURAL BARRIERS IS NOT ENOUGH

Elsie D. Helsel, Ph.D.

March 23, 1968

Grateful as we are for the national attention being given to the removal of architectural barriers from buildings, it is not enough to assure the physically handicapped cerebral palsied individual adequate architectural support for a truly adequate program to meet needs. We need an informed change of attitude and a commitment to action on the part of professional people responsible for the care, treatment and training of the nonambulatory cerebral palsied individual from programming that segregates to program planning that integrates. We can scarcely blame architects for designing isolation units for the nonambulatory cerebral palsied when programmers give them wrong advice, when they tell them, for example, there will be so many "bedfast" patients - plan a unit for them. Or they tell a school architect - we will use home instruction for those severely physically disabled who would be too difficult to manage in a group setting in a classroom. Some of the specific service needs that we of United Cerebral Palsy have a responsibility for bringing to the attention of architects are: (1) barrier-free construction throughout so that progressive patient care or progressive school management can be a reality; (2) space designed that permits appropriate and stimulating programming; (3) space designed for bulky equipment so that those who can be gotten out of bed into any kind of supportive equipment - wheelchair, litter cart, tilt table, etc. can have storage space at beside for the equipment and room to maneuver wherever they need to go - dining room, school room, activity room, outside space; (4) surfaces that enhance mobility - not rock-hard terrazzo for the toddlers or scratchy carpeting for babies learning to creep or crawl; (5) space that allows for the three sociopetal zones - a space of one's own where an individual can have complete privacy; a space where the individual can be with a few friends; space where the individual can be with a larger group; (6) beauty, color, and texture in the environment that are stimulating - especially for those who must spend some time in bed.

# FACILITATION OF SPECIAL EDUCATION PROGRAMMING THROUGH ARCHITECTURE

Henry Bertness, Ph.D.
Assistant Superintendent
Pupil Personnel Services
Tacoma Public Schools
Tacoma, Washington

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
Rice Hotel, Houston, Texas March 23, 1968

A bit over ten years ago, several of us had the task of suggesting future directions for the education of exceptional children in our state. It was during this time that I visited a school and saw quite a number of severely handicapped children. One was a girl who was severely involved with cerebral palsy but whose big toe had been discovered a few months earlier. She had some control over her big toe and with the assistance of a specially rigged electric typewriter it was found she could communicate. One of her teachers explained what my function was and asked her if she had anything to say to me. She look at me for a while and then, with her big toe, tapped out a message on her typewriter. For a long time I carried this message in my wallet, but now I can't find it. It probably was worn out. I do remember the sense of the message and it was, "Above all, regardless of what I look like, remember that I am a girl, just a girl, with the same feelings as other girls."

They say form follows function. We can add that function depends on your point of view toward the situation; and, in education, toward children. What is developed in program and facilities and staff for children with handicaps in a school district depends largely on the points of view that the people of that school district have regarding handicapped children. In the Tacoma Public Schools we have developed and are developing certain major points of view regarding children with handicaps. These points of view have led us away from separate facilities for handicapped children to facilities that are integrated with general facilities but still retain the necessary unique characteristics for serving handicapped children. Hence, our functions serve our points of view and our form serves our functions.

First of all, we have a point of view regarding the child with handicapping conditions. We consider this person, first, a child. We consider him more like other children than unique. We consider him a child and we take our cue from him and from all children.

Secondly, we grant first class citizenship to the child with handicaps and, therefore, seek to develop whatever special programs are needed by him to progress. Further, we make all other parts of the school program available to him as appropriate.

Thirdly, we feel that there should be no either/or with respect to the basic placement of the child in ths chool milieu. Again, we don't believe that we should build special and separate facilities for handicapped children, for that would necessitate the either/or ... (Either he is in the separate and special facility or he is in the regular school building.) We feel that this either/or is unnecessary.

Fourthly, in order to make best use of our facilities which are built together with general facilities, we make use of a concept which we call progressive inclusion. Progressive inclusion means that if it is to the advantage of the child to be wheeled down the hall in order to see other children, we wheel him down the hall if but for five minutes. If it is to his benefit to be included in a fourth grade class for fifteen minutes, he is included for fifteen minutes. Tomorrow, maybe nothing. Tomorrow, maybe thirty minutes. The either/or is not there. We can go it so far and in whatever ways appropriate to the child.

Fifthly, we have developed an interdisciplinary team approach in working with the child. Our physical setup, our program, and our staff are committed to this business of working together, crossing the hall together, going down the hall and in all ways trying to serve the child in an interdisciplinary and articulated manner.

We work with children from the age of three and up to age twenty-one, depending on their situation. In our state we are prevented from working formally and regularly with children under the age of three, but our staff are very concerned with the very tiny ones, the children who will be in our program in just a while. Therefore, we do not hesitate to give consultant help to families who have found that they have a handicapped child. Nor do we hesitate to work with these families in diagnostic and planning ways prior to their actually entering school at age three. Some people would call this bootlegging; we call it sensible and we call it planning!

Now, I would like to introduce you to our program and facilities in somewhat the style of a child. To help us we have some slides of different parts of our program.

Children are important in Tacoma, all children, all kinds of children, all shapes and forms, all children. Because of this we have a happy school. Take a look at some of our classes. Here you see us and we're doing all sorts of things. We have nice classrooms and we enjoy each other.

Here we are on the playground. We have a special playground when we want to play by ourselves and we also go out on the big playground where we meet many of our friends who are in other parts of the school.

Just across the hall from our classes are some very big spaces. They have all kinds of things in those big spaces to help us learn how to walk a little better and use our arms a little better, all sorts of things. Occupational therapists and physical therapists help us here and again, it's a happy place.

Right around this big space, we have some smaller offices. We do many things in these smaller offices. A social worker works with some of us and a speech therapist works with many of us, and once in awhile we have a hearing problem and then an audiologist tests our hearing.

That's a hard word to pronounce. Once in awhile, a psychologist comes around and gives us all kinds of interesting things to do, and because of what he learns about us we get a better program.

We get other interesting things to do in our classrooms. Oh yes, we have some very small ones here, and here is one who is taking a bath. I think they call it hydrotherapy. They are also working on some kind of speech lesson. I think that is why the telephone is there.

Every once in awhile our doctor comes to school and he tells our teachers and our therapists and others who work with us how to help us. They tell him a few things, too. The doctor consults, they say.

We ride busses to our school and we go to many things in the community, but one of the places that is most fun is the big swimming pool. We go there quite often. Here we are swimming.

We have many friends in school. Some of these friends don't spend much time in therapy -- they don't have to, but they're in class and sometimes they come and help us in all kinds of ways. They help us with our games and they help us in their classes and they help us read and they help us feed ourselves. These are our friends.

Some of the people who are in school are awfully young. We don't know how they slip in but there are some awfully young kids who come here. I guess it's all right because a little later on they come and stay in our classes.

We all look forward to going down the hall. Going down the hall means lots of things. It means seeing our friends, it means working on things like getting around, and it means going to our second classroom. You see, we have our special classroom where there aren't too many of us and then we have our other classroom in the other part of the school where we meet many of our other friends.

There are lots of children in my school, all kinds of children. They are happy children. We have a happy school.

Now, ladies and gentlemen, it is easy to become sentimental about these ideas. But this is not sentimentality; this is practicality. If handicapped children are to become as much a part of the mainstream of children as possible, then we simply must destroy the either/or necessity in our architecture, our programs and our staffing. We also must provide for this inclusion to be done progressively. Again, it is not very smart to demand that a child be completely ready to be included in a so called regular situation before he is included. If we want to implement these ideas then we build our special facilities along with the general school.

We wish you could come to Tacoma to visit us and see how we are trying to implement these ideas but we are not finished. Open-endedness is the bugle call since better ideas are always in the making. We hope to continue improving but, above all to make our schools places where handicapped children can be accomodated easily and happily.

# SOME SECOND THOUGHTS ON PLANNING
# A RESIDENTIAL CENTER FOR THE MENTALLY RETARDED

Harvey A. Stevens
Superintendent
Central Wisconsin Colony and Training School
Madison, Wisconsin

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS, INC. 1968 ANNUAL CONFERENCE

March 23, 1968 Rice Hotel, Houston, Texas

## Introduction:

My comments will be based essentially upon past experiences in three different types of facilities for the mentally retarded: The first, a multipurpose residential center, served all ages and all degrees of mental retardation. A wide variety of programs were conducted. Some remodeling was undertaken and 400 beds were added to serve primarily the profoundly and severely retarded. The second was a specialized research-educational-vocational rehabilitation residential center. The population was school age and appropriate and extensive programs were organized. The facility originally was a 350-bed vocational-agricultural school. It required extensive "remodeling."

The third facility is an entirely new, specialized residential center serving profoundly and severely mentally retarded. Many are non-ambulant with gross physically handicapping conditions. Extensive medical, paramedical, nursing care, rehabilitation and education services are offered. In addition, an extensive biological and behavioral research program is conducted, as well as active participation in the training of professional and technical personnel. It also operates a statewide diagnostic and evaluation service, a comprehensive preprogramming service and outpatient dental care.

It must be noted that it is extremely difficult to identify and verbalize one's own errors of omission and commission. My ego demands that I state my point of view and identify the errors by assuming a positive posture. It will be your task and responsibility to convert the positive statements being errors -- or second thoughts -- regarding planning a residential facility to serve the mentally retarded.

Let me assure you that actively participating in establishing and conducting two "New" residential centers is sufficient for one professional career! At least, I won't plan to assume responsibility for planning any additional ones. I was recently told that I am now in the "twilight years" of my professional career. This is a new concept to me. I learned upon further investigation that this means you have about ten years of a paid professional career remaining before retirement.

I have found it somewhat difficult to respond to the task assigned me. Yet, it has proved to be a challenging one as I attempted to "think" about doing the next facility differently.

The task is a difficult one because there are no guidelines or criteria that have been validated to assist one in making an appraisal. One must, therefore, rely upon "professional judgement", "lay opinions" and "impressions of staff, patients" and, yes, even the "residents".

## Factors Influencing the Design and Function

At the outset, one must recognize that a variety of variables have come into sharp focus since the conception and finalizing of the architectural plans. One must also accept the fact that honest, well-meaning people participated in delineating the programs which the architect converted into meaningful and functional space relationships. Let us briefly look at some of these factors.

1. The introduction and availability of new knowledge and information by research after completion of the architectural plans. It is extremely difficult to visualize the residential center of the future. We cannot accurately predict the impact that preventive measures will have on a reduction in the prevalence of the mentally retarded. It is too early to estimate the influence of controlled family planning upon mental retardation having a demonstrated genetic basis.

One also needs to recognize that you need to conceptualize a residential center as being a self-contained unit; that it is dependent upon community resources for only a relatively few services.

We should also assume that the facility will be constructed in compliance with all required building codes. It should be noted that this isn't always done! Ten years after construction, the state building inspector condemned elevators in a residents building. The original specifications required "freight" elevators instead of passenger elevators. These must now be changed -- a costly "error". Approved construction practices in some of the Western European countries would not meet most state building construction codes.

## Areas Requiring Change

It is necessary that one view the functioning of an institution in relationship to "time." We need to somehow conceptualize the residential center of the future if we are to critically evaluate existing facilities. One needs to realize that the residential center of the future will be an extension of community services for the mentally retarded. One needs to accept the fact that the residential center of the future will serve primarily the profoundly and severely mentally retarded -- many with multiple handicapping conditions; that it will serve an increased number of emotionally disturbed, mentally retarded and a variety of mentally retarded who cannot be served at home or by a community-based service. The center will provide opportunities for staff to actively participate in basic and applied research.

The center's programs will be closely integrated with universities and colleges in order to increase the manpower requirements in the professional and technical areas. There will be a greater utilization of professional consultants from the community in planning, organizing and conducting residential programs. The resident center staff will find itself being utilized by community agencies to help their staff increase their skills in working with the mentally retarded. The administrators of the residential center will place greater emphasis upon staff utilization through increased staff development and inservice education programs. These and other factors will influence the architectural design of future facilities.

One must not neglect to consider that the culture in which the facility is to be located and the geographical area it will serve will influence the design and its ultimate function. One must constantly be alert to the biases of the various disciplines and to political influences. And, finally, one must recognize the basic principles that influence design. My particular bias suggests that "form follows function" -- one not always accepted by architects. In this respect, I have seen some "new facilities" where it became evident -- to me, at least -- that the architect disregarded"function" in order to achieve a particular "aesthetic" appearance!

## Specific Suggestions

### Location of Site

In selecting the site, one should, if possible, disregard the opinions of vested interest groups. The site might have some of the following characteristics: it should be located near an adequate source of professional, technical and supportive labor. It should be easily reached by public transportation and good roads. There should be ample land to prevent crowding of buildings. (I am not sure about multiple-story buildings located in densely populated, high-land-cost areas.) There should be sufficient space to allow a variety of recreational areas. There must be access to fire and police protection. There should be access to and acceptance by interested and supportive university and college faculty. In order to attract and hold well-qualified personnel, the site should be easily accessible to cultural activities. Opportunities to participate in community affairs, available professional organizations to eliminate or minimize professional isolation; and in an area with a relatively low crime and delinquency rate. Constructing adjacent or contiguous to a mental hospital in order to avoid duplication of costly utility service needs to be very carefully considered. These and other factors are important in relationship to selecting a desirable site.

### Selection and Role of the Architect

In some instances the utilization of a state architect may be both limiting and restrictive to achieving a dynamic design. They are frequently inclined to be conservative in their approach to achieving more effective space utilization through a "radical" design. They sometimes are restricted in utilizing new materials and equipment.

This has also proven to be an advantage. Initial costs may be given priority in both design and materials when compared to long-term recurring maintenance cost. The same points can also be used for an experienced architect, or an architectural firm from the private sector. Frankly, I would prefer utilizing an experienced architectural firm to design the residential centers. However, I would want and insist upon a non-political procedure for selecting the architectural firm.

## Defining the Program to Aid in Architectural Design

It is necessary that the "owner" provide the architect with a very carefully prepared "program statement". This will not only aid the architect in achieving his purpose, but will greatly aid the staff in implementing the program. Let me briefly comment upon my most recent experience in this area. The original goals were clearly delineated and now, almost fifteen years since their conception, they are adequate for the present and the foreseeable future. The governing board, the administration department and the legislature accepted these goals, in principle, when creating the center. Problems in achieving a satisfactory design were immediately encountered. First, in an attempt to save time and money, it was felt that a building designed ten years previously could be modified to meet the needs of the specialized population. This problem was compounded because no similar state or private facility - in this country or in Western Europe - had a similar program. There was also a shortage or a nonexistence of professional consultants to help delineate these new programs and combinations of programs. As a result, the state architect assumed an ultraconservative approach to the resolution of the problems encountered in the design. Some difficulties were encountered because of the delay in defining the role of the nearby medical school. This was also true for the school of education, the school of social work, the department of psychology, etc. There was a sort of "come back and see us when you have something specific to offer us" response. This, coupled with frequent changes in deans, department heads, and faculty, further complicated matters. (The situation is greatly improved today.) There was also a lack of recognition by program planners that eventually, by focusing intensively a wide range of professional services upon a single resident, dramatic changes in the resident's ability would be achieved in a relatively short period of time. Thus, the staff was soon confronted with inadequate space to respond to the improved condition of the resident.

## The Size of the Residential Center

An entire conference could be devoted to delineating or determining the appropriate size of an institution. My position on the size of institutions has been clearly stated for some time. I maintain that the size must relate itself to the purpose of the facility. One needs to consider if it is to be a specialized or a multipurpose facility. One must predetermine if it is to serve a region or a community. The trend, as previously suggested, is toward specialized facilities. In my opinion, a facility serving only the emotionally disturbed mentally retarded should not serve more than one hundred residents.

A facility serving only "defective delinquents" (whatever that is) should not exceed 125 to 150. A facility serving as an educational-vocational rehabilitation center should not exceed 350. A residential facility serving profoundly and severely mentally retarded could efficiently and economically serve between 500 and 750 residents. I, reluctantly, point out that the Central Wisconsin Colony and Training School now has a rated capacity of 1,268. The last 240 beds occurred as a "political accident". Yet, we still plan to add about 200 more beds in eight separate "cottages". One unit will house our extended vocational rehabilitation clients and the remaining seven will serve "social, emotional, and behavioral" problem residents. The administrative organization developed to carry out the programs will have a marked impact upon the effectiveness and efficiency of the center. In recent years the "unit" system has been conceived to bring professional services to the resident in a more efficient manner. This concept is contrasted to the centralized organization. The key to success, in my opinion, must be based upon an interdisciplinary approach; the multidisciplinary and monodisciplinary approach has marked limitations. In some instances, it amounts to "professional blackmail". Whichever approach is used, it will have a marked influence upon space utilization.

## Size of Residents' Living Unit(s)

Again one must recognize that the size and type of living space required or provided the resident is directly related to the type and number of residents being served. One needs to determine what is a reasonable number of residents to which one aide can effectively, efficiently, and economically provide care. This might well serve as the size for the "basic care unit". This concept should not be confused with the building size, although it will have a bearing on its ultimate size. In recent years the concept of "group care" has emerged, i.e., how many one employee can effectively care for during an eight-hour period of work. It is now accepted that the first and second work shift should have the same number of staff, e.g., for totally dependent, eight to ten patients may be a desirable work load. For semi-dependent, ten to twelve may be adequate. For totally independent, ten to fifteen may be sufficient. Experience would seem to suggest that living or service units should not exceed 25. Such areas could be conveniently and easily divided by partitions or small rooms.

## Sleeping Areas

Sleeping areas need more attention than previously given. The need for single rooms, two beds per room (never three!), some four-bed and some six-bed rooms. It is conceivable that 20-25 residents can be adequately accomodated in an attractively designed room using partitions to divide the area.

## Recreational Area

Provisions need to be made for the individual to have his own "recreational" area. Small areas are also required for "quiet" activities as well as for large group activities. Access to outdoor recreational areas should be provided. Concrete surfaced play areas, without shaded protection, could result in large, unusable areas. Concrete retains heat for a long period of time. Also, there need to be provided multi-purpose rooms for arts and crafts types of activities.

In most residential areas, there must be provided adequate heating, ventilation and good humidity control. Frequent air exchange is necessary for most areas.

Most dining areas make it difficult to develop and conduct adequate self-feeding programs.

More attention should be given to the development of suitable areas for visitors. Some areas which afford more privacy are needed. Ramps need to be provided for visitors requiring wheelchairs.

For the older residents, facilities for "sheltered workshop" types of activities are desirable within the living unit.

## Materials

Not much needs to be stated concerning types of materials. Suffice it to say that they must be durable, attractive, easy to maintain and service, have a reasonable life use expectancy, be easy to clean, and economically installed. It must be stressed that infectious diseases can be spread through the use of unsatisfactory or unsuitable material. One would wonder how safe "carpeted" areas would be for residents suffering from shigella or infectious hepititis -- diseases usually found today in most residential centers for the mentally retarded. Architectural design for living areas should be suited to the type of residents being served and for the purpose of the area. One would find it extremely difficult to adequately provide suitable and effective medical-nursing care in a residential unit designed with a "home-like" atmosphere. However, older more independent residents could and should be provided with a home-like living environment.

## Treatment-Rehabilitation-Educational Areas

The need for adequate acute medical and surgical units is frequently self-evident. The utilization of community hospitals needs to be carefully considered. In some instances, the community facilities have been only reluctantly made available to them. One needs to recognize that job satisfaction is required to keep good professional personnel. Having them employed only to send "interesting cases" to outside consultants reduces "job satisfaction". If such services are provided, then adequate and well-staffed clinical laboratories are essential. Sufficient isolation areas for infectious diseases are essential. There must also be incorporated sufficient and suitable space for physical therapy and occupational therapy. Specialized areas as well as space on residential units is desirable. Dental care units need to be provided. Staff time may be more effectively utilized if, in addition to the usual dental suite, space for a dental hygienist is made available within residential units. Good medical programs require the utilization of numerous medical specialists. This dictates the need for desirable and suitable work areas, e.g., dermatology, neurology, psychiatry, pediatrics, medical genetics, orthopedics, etc. No residential center should be operating without a well-defined pharmaceutical program. Abuse in receiving, storing, dispensing and administering drugs has become a national concern. Centralized and vocational rehabilitation have assumed a greater importance in recent years. More emphasis is being placed upon these areas because of their relationship to preparation of the residents for early returns to their own family or to the community. Physical facilities need to be modeled after the latest designs being used in similar community-based programs. Special consideration needs to be given to children with multiple handicapping conditions, physical and sensory defects, as well as the emotionally disturbed individual. In recent years "evening" classes have been organized for the adult mentally retarded. This becomes an excellent way to develop meaningful programs relating to "worthwhile use of leisure time" as well as to improve basic educational skills in reading, writing and arithmetic. Attention is also being given to arts and crafts activities. Suitable space is required for those activities. The utilization of volunteers has significantly increased in all types of programs for the mentally retarded. These groups require a variety of assigned space for (1) storage of clothing, (2) preparation areas, (3) conference areas, (4) work areas, etc. The type of area and space will be totally dependent upon how these individuals are incorporated into the total program.

Personnel Areas

It was previously suggested that increased emphasis would be placed upon staff development and in-service training programs. In recent years there has been a need for an "educational information center". This would be a library, but not in the historic or traditional sense. A well-qualified librarian, with adequate staff, is essential to keeping programs current and updated. The "explosion" of information in this field demands that this type of facility be provided. It is no longer a "frill". Many audio-visual aids are now available to assist in teaching and improving staff performance. Space is required for preparing, previewing and storing this material. Closed circuit television, along with video tape recording, is becoming a part of progressive programs. Provisions for their use are necessary in new facilities. It is apparent that employees working continuously with mentally retarded individuals need frequent "breaks". They should be provided with their own "break" areas as well as eating areas. Skills in eating can be taught without having the employee eat with the patient. As state employees move rapidly into collective bargaining, these areas may become negotiable in collective bargaining. The maintenance of the health of employees is basic to good programs and helps reduce personnel turnover. An active employee health service is essential. This necessitates having space available for (1) first aid and (2) physical examinations. Institutions that have installed shower facilities for employees have found that they are used only infrequently and then chiefly by maintenance personnel! Many newer institutions are being constructed contiguous to cities, thus eliminating the need for housing of employees. It no longer is necessary to provide this as an inducement for employment. If at all possible, all employees should live within the adjacent community. Rooms should be provided for the infrequent "visiting firemen". Surprisingly little attention has been given to providing employees with adequate space for storing personal clothing, changing into work clothes, and particularly a locked cabinet for women to keep their purses. Adequate parking for employees -- apart from visitors -- is essential. Undergraduate and graduate students participating in a field practicum need adequate work space -- particularly office space -- though not necessarily separate offices. Separate space to work with residents is essential to a successful university affiliation.

## Research Activities

We need to recognize that residential centers, regardless of the type of patients being served, are "living laboratories" and a source of supply for research subjects. In design, serious consideration must be given to providing a wide variety of research space for both biological and behavioral sciences -- for both basic and applied research. These spaces need to be designed so they can be easily changed as research projects change. Adequate animal space is needed for experimental animals. Sufficient air conditioning, frequent air exchanges and sanitation are necessary in most research areas. A maintenance shop is essential for repair and manufacture of specialized research equipment.

## Supporting Services

It is essential that separate units be designed for (1) warehouse, (2) vehicle storage and repair, (3) grounds equipment, (4) food service and (5) laundry. To incorporate them into living units is a serious error. A wide variety of "visitors" come to most residential centers. They need adequate directional signs in order to reach the appropriate building to see the appropriate personnel or resident. Management services, personnel and payroll, and business offices are demanding more space. Data processing is placing an increased demand upon all of these services for specialized space. An internal paging and telephone system reaching all areas are essential and lead to efficient use of professional staff. With increased communication and staff interaction, there is a need for a number of small conference or meeting rooms -- all designed for the audiovisual aids. Space suitable for 15-25 individuals is necessary as well as a small auditorium for about 150 people. A road system within the center which discourages local through-traffic is desirable. Intensive study needs to be given to providing adequate storage space for residents' personal clothing as well as other clothing and linens. The disposal of soiled clothing needs intensive study. Too frequently this is overlooked and results in higher levels of unpleasant odors. Dead records and microfilming storage needs to be given attention in the administrative units. Adequate methods and storage areas are required for trash and garbage.

Let me assure you that my state has been most responsive to the needs of its handicapped citizens. They are adequately supporting our budgets and providing us with ample personnel. It has been our lack of foresight which has slowed the development of our programs. The old adage that "hindsight is better than foresight" is true in our case. Let me assure you that our staff is working hard to adapt programs so they can be effectively and efficiently conducted in existing facilities.

## Summary Statement

What we do for people is a reflection of our cultural and social mores and historical practices. What we do for people is a reflection of how capable we are of utilizing available knowledge and incorporating it into current practices. What we plan to do for people is a reflection of how capable and willing we are to evaluate the present in light of new knowledge and past experiences. We must recognize that in the final analysis what we do is a reflection of the value we place on all individuals -- handicapped, disadvantaged and disabled.

## SUMMARY
## CONFERENCE PRESENTATION

# ROLE OF ARCHITECTURAL PSYCHOLOGISTS IN DEVELOPING MORE EFFECTIVE SERVICES

Calvin W. Taylor, Ph.D.

Present at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE

March 23, 1968 Rice Hotel, Houston, Texas

Our architectural psychology program was designed to link the fields of architecture and psychology (the initial one of the behavioral sciences), hopefully to the mutual benefit of both, and especially to benefit the people for whom manmade environments are ultimately designed. A main emphasis has been a graduate training program which for seven years has been producing students who are trained in both fields and prepared to do research and other work in the heretofore largely unexplored but still vital areas between the two fields. This is a reasonable team, because architects design environments for people and psychologists study the reactions of people to environments. We helped to catalyze awareness and increased efforts through our first two international research conferences (largely supported by UCPA) on architectural psychology held in 1961 and 1966 (The University of Utah Press will publish a volume this year emerging from these conferences). There has been a rapid awakening the past handful of years to the importance and urgent needs to move rapidly ahead in as many ways and directions as possible between architecture and the behavioral sciences.

One straightforward contribution is to increase tremendously the feedback loop between the reactions and suggestions from occupants of new (and older) buildings to the architects who are in process of designing future buildings. Available psychological measurement techniques and research designs are available for use in naturalistic settings to facilitate this process. Many, many other well planned experimental studies in multidimensional architectural environments with one or more variables manipulated also are occurring. Not only can friction points and architectural barriers be reduced or eliminated but insights into man-enviornmental relations can increase so that man can function in physical environments where his weaknesses and handicaps are designed out as far as possible. It is also becoming feasible that better environments can be built so that each person's greatest potential assets might have a greatly increased chance of being developed and cultivated so they are more fully functioning. In other words, the positive approach of moving rapidly to design environments that will enable man to reach his highest levels and thus create a better world for man and therefore a better man. A final point will be made that there are high-level talents heretofore dormant, neglected, or even stifled, that we now know how to identify and cultivate in our school while students are simultaneously acquiring knowledge. By looking at the assets of each student the evidence is that almost all students will be above average in learning knowledge through at least one talent and we can easily double or even triple the per cent who are highly gifted by using this multiple talent approach. In summary, by two positive approaches of learning how to design better environments for people and of using a multiple talent approach in schools, we can move rapidly toward finding that handicaps can be almost designed out and that almost all persons are promising people and can live and enjoy a fruitful life through more full and unhampered use of their potential assets.

## General Information About the Architectural Psychology Program at Utah

Long neglected by designers and scientists alike, the effects of the architectural environment are now being explored in earnest. The program at the University of Utah has struggled against the inertia of the past to establish a unified program of advanced training aimed at producing personnel for research in the relations of architectural environment to human behavior. The interface between designer and scientist has been a source of predictable conflict to the fledgling discipline. The program is presently supported by the National Institute of Mental Health with six traineeships. The program leads to a doctoral degree in psychology, with a minor in architecture. The University has provided a separate building to house the activities of the program, including the initiation of research. Further support from the University includes facilities to be used in this program in new buildings, now designed for both architecture and psychology. The University has also expressed willingness to provide a site for a future research laboratory for this program.

It should be emphasized that this so far has been essentially a training program and is producing personnel capable of working in the area between the two fields. There is an increased interest in the hiring potential of graduates of the program, as evidenced by a number of universities inquiring about our graduates as staff candidates. Recently four placements of our students have occurred in almost ideal settings. Following early efforts in 1958 to establish research in the direction of the relations of environment to behavior, we held a two-day NIMH-supported conference in 1961 with fifteen experts from the United States and Canada to discuss the feasibility of combining architecture and psychology and medicine (psychiatry) in a program of research combining these fields. The training program was established in 1961, as a result of our first conference. Subsequently, the trainees have engaged in two NIMH research contracts (1964, 1965) resulting in reports on the design of new mental health facilities. Other products of the program, including theses and dissertations completed or nearing completion are listed on the reverse side of this sheet.

Our(1966) International Conference on Architectural Psychology was supported by the American Nurses Foundation, Educational Facilities Laboratory of the Ford Foundation, Easter Seal Research Foundation, Maurice Falk Medical Fund and the United Cerebral Palsy Research and Educational Foundation. It was attended by some eighty-five researchers and experts from the United States, Canada, Scotland and England. This conference left little doubt as to the importance of research from the combined disciplines of architecture and the behavioral sciences. The 1966 conference also proved to be an exciting first-hand experience for all of our trainees. Since then, we have continued to have visitors to our program from architecture and from the various behavioral sciences each year, and more formally this year we instituted a "visiting professor" seminar.

The Architectural Psychology Newsletter began as a quarterly publication in November 1967. It now has subscribers from all parts of the world. The purpose of the Newsletter is to communicate among researchers and practicioners, the ideas, methodologies, and findings that are currently developed in the relatively uncharted areas between the social and behavioral sciences and environmental design.

We now have funds in hand, as well as trained research personnel and facilities, to build and operate an experimental room whose architectural features can be manipulated and studied either on single independent variable or multiple independent variable bases.

## Architectural Psychology Graduate Training Program -- University of Utah

The Architectural Psychology Training Program accepts qualified graduates from architecture, psychology and other relevant fields. The program was formally started in 1961 by Roger Bailey, FAIA, Professor of Architecture and Calvin W. Taylor, Ph.D., Professor of Psychology (Co-Directors of the program), and is supported with six Public Health (NIMH) Traineeships by the National Institute of Mental Health. The program is housed in building 403 (Bridger Hall). The facility offers space to accommodate shops and experimental areas, as well as providing for the training program needs.

### Degrees Offered

Masters in Psychology and/or Architecture; Doctorate in Psychology.

### Masters Theses

(1) The Kibbutz in Israel: A Community Study and Planning Project, 1964, Donald P. Grant.
(2) An Environmental Analysis Laboratory, 1964, Joseph M. Vykopal.
(3) Architectural Psychology - The Development of a System and Behavioral Science Findings, 1965, A. J. Bate.
(4) The Meaning of Color, 1965, J. Courtney Black.
(5) Architectural Psychology - An Initial Study, 1965, Robert Wehrli.

(6) The Influence of Hue and Illumination on the Interpretation of Emotions, 1967, Imre Ransome Kohn.
(7) Behavioral Criteria in Building Design, 1967, George V. Trieschmann.
(8) Residence Hall Environment - An Architectural Psychology Comparative Study at the University of Utah (expected 1968), Victor Hsia.
(9) Behavioral Criteria in an Analysis of the University of Utah Student Union Building (expected 1968), Lee Burnham.
(10) The Design of Social Intersections (expected 1968), John Archea.

## Doctoral Dissertations

(1) Open-Ended Problem Solving in Design (expected 1968), Robert Wehrli.
(2) Housing Space and Space Use (expected 1968), J. Courtney Black.
(3) Open-Plan versus Closed-Plan Schools (expected 1968), George Trieschmann.
(4) Some Verbal Dimensions of Architectural Space Perception (expected 1968), John B. Collins.

## NIMH-Supported Research Projects

(1) Community Mental Health Centers, An Architectural Guide, 1964, Bailey, Bate, Black, Ellis and McAffee.
(2) Mental Health Facilities for Inpatient Adolescents, 1965, Bailey, Black, Ellis and Kohn (mimeographed).

## Architectural Psychology Newsletter

This first newsletter in this field was initiated this academic year by John Archea with the assistance of Victor Hsia, two trainees in the architectural psychology program. It is published quarterly and the two issues to date have been almost completely supported by its growing list of international subscribers (researchers and practicioners in this field).

## Two International Research Conferences

Each conference in this series has attracted nearly all of the 20 leading researchers in this field from the United States and Canada at both conferences and also from England and Scotland in the second conference. More than half of the 85 participants and observers who attended the 1966 conference made a presentation on one of the several topics covered.

First (1961) Exploratory Research Conference on Architectural Psychology and Psychiatry (Mimeographed 219 page report, 1966), February 24-25.

Second (1966) Research Conference on Architectural Psychology, May' 26-28, Park City, Utah (Mimeographed 500 page report, 1968).

NOTE: Before the end of 1968, THE UNIVERSITY OF UTAH PRESS plans to publish an economical paperback book covering both conferences. This book will provide another attempt, with the conferences, to stimulate interest and greater human efforts in this field.

# PROVIDING MEDICAL CARE TO SEVERELY HANDICAPPED PERSONS IN RESIDENTIAL FACILITIES

Robert B. Kugel, M.D.
University of Nebraska
Omaha, Nebraska

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 22, 1968 Rice Hotel, Houston, Texas

In 1967, the President's Committee on Mental Retardation took stock of the national effort being made to combat mental retardation. In the published report, MR:67, one of ten points emphasized was the poor status of residential care. In fact residential facilities were described as a national disgrace.

Most of what I have to say today will be an effort to discuss the poor showing. Unfortunately, I can bring you little good news when talking about residential facilities. I think it is important, however, at the outset to point out that, in the United States, considerable progress is being made in some areas, much of it outstanding. One should not overlook the significance of some of the successes, such as the help provided by the public health nurses. The significant effects of parent education, of occupational day centers for severely handicapped individuals and employment opportunities for the retarded and the handicapped should be recorded. Throughout the country, new programs have developed in public education which have helped to dispel some of the darkness. Research biological, sociological and behavioral is a hallmark of the American scene. Volunteer efforts, for both the retarded and the physically handicapped, have been outstanding. More recently new innovations in behavior shaping have pointed the way to better management. Diagnostic services for the retarded also have been among the outstanding successes.

Why have the residential facilities in this country lagged so far behind these other areas in which advancement has been considerable? What are some of the problems which seem to confront our residential facilities? In many places a public residential facility has been plagued by a triple problem - overcrowding, understaffing and underfinancing. To complicate matters, the public long accustomed to knowing little about mental retardation, often had inaccurate information which was replete with a mystique about the retarded and other handicapping conditions which suggested hopelessness, repulsion and fear. Gradually a change in attitude has been occurring as various significant efforts have been made to enlighten lay and professional people alike. But, despite these efforts, the residential facilities of this country have languished.

I would like to analyze briefly some of the reasons why public and private residential facilities throughout the country have fallen on such hard times. Before starting however, it would be well to point out that the problems related to physically handicapped individuals who reside in residential facilities do not differ from those who are not physically handicapped. Unfortunately, many residential facilities were built in an era when the planners of these facilities were largely committed to locating them away from the population centers of the state. This unfortunate decision seems to have been motivated in part from the conviction that the mentally retarded person was best cared for in more bucolic settings; in part out of fear that the retarded, being a scourge to society, should be removed as far from society as possible; and, in part, to satisfy the yearning to have a state facility in a certain town in order to provide additional revenue for that community.

One should further note something of the history of our residential facilities. In the late 19th century there was a wave of optimism about the care of the mentally retarded. The general belief at that time was that through educational efforts the retarded could be helped, indeed cured. When this concept, so noble in its beginning proved wrong it was supplanted by the scourge notion promulgated by Goddard and designed from his poorly designed study of the Kallikaks. The mentally retarded were soon to overpopulate our society, according to Goddard, and segregating them from our society was the most important service to be rendered. As a consequence, further building programs for institutions were really a continuation of the out-of-sight, out-of-mind concept. Still later institutions for the retarded began to be considered as colonies where the undesirable members of society would be segregated and separated. This concept also proved to be fallacious, but, unfortunately, the country had entered World War I to be followed not long afterward by the great depression. These factors further contributed to the reason why little in the way of changes occurred.

For whatever reason or combination of reasons most of the nation's public residential facilities and also the private ones are located in out of the way communities. Being so located has meant an ever increasing difficulty in obtaining highly qualified staff who frequently have preferred to live in larger communities. Similarly, the core of any institution, the ward or cottage personnel have been increasingly difficult to recruit as people have moved to larger metropolitan areas.

When citizens become concerned about an issue such as where to locate a new highway or whether to build a new school, it has always been useful to be able to show these citizens, their legislators and others in decision making positions what the problem is all about by having ready access to an existing example. None of this is available to those trying to change the plight of the institution. Is there an exemplary model of care for the severe and profoundly retarded to be seen anywhere in this country? Citizen groups must make a great effort to come to the facility and then often only once. In part, this is so because of the distance involved for many and in part because they were repulsed by what they saw. Many legislators have appropriated large sums of money to support their public facilities but have never visited a single institution for the retarded. There are physicians who refer patients to these residential facilities but who have never seen the facility and do not know the professional personnel caring for the clients whom they refer. This is an odd paradox since one cannot imagine a physician referring a patient to a facility for a complex operation procedure if he knew nothing about the place and knew nothing about the people who were there. As a consequence public and professional indifference and misinformation abounds. Token increases to the budget have been made so that very little help is given to the beleaguered institutional superintendent and his staff.

Salaries have often been at shockingly low levels. Professional salaries have often been at levels so low as to attract no one of competence and the nonprofessional salaries for attendant personnel in many places have been below the national poverty level! Can anyone doubt that such practices have served to interfere further with effective programming?

Many institutions have been so hard put to attract capable medical personnel that they have relied heavily on foreign-trained physicians some of whom were unable to acquire state licenses and, hence, were only able to work in a facility which could waive state requirements such as is possible by a state facility. In such cases these men find themselves in virtual bondage, unable to go elsewhere and being the only ones willing to accept poor salaries.

Patient help constitutes another problem sometimes referred to as institutional peonage. Although some work placements may be indicated, the continued retention of patients in work situations has often been the only way the daily work could get done. Such important activities as the laundry, food service, and ward service in the hospital would collapse if it were not for the continued reliance on patient help. In addition, the failure to have adequate community resources - workshops, group living facilities, and rest homes - has meant that even if patients were to be released there is often no place for them to live and no job for them to have. To rehabilitate the retarded person who has lived most of his life in an institution becomes much more difficult since he is ill prepared to cope with the social requirements of a normal community.

The American Association on Mental Deficiency is currently in a period of evaluating many of our residential facilities. This is a voluntary movement and not all residential facilities are obliged to submit. However, of those that do many are reporting that they are grossly overcrowded, anywhere from 25 to 50% more than their rated bed capacity. The figures are not readily available to ascertain whether the physically handicapped fare better than the non-physically handicapped. On the basis of personal observations on the part of many people it would seem that there is no reason to think that this group does indeed fare any better. Consequently, there are often large bleak wards where physically handicapped individuals are confined to bed, provided with basic nursing care butgiven little in the way of overall stimulation to make their lives the least bit meaningful. Many will end their days in drab surroundings with little to afford them any interest. There is still an additional factor. The growing population at many residential facilities is made worse because there are now patients who would have died a generation ago, but medical advances now can manage infectious processes much better.

The underfinancing of most public institutions is a tremendous problem. The per diem costs over the country range from $3 to $12. Most zoos spend more than this for their large animals on a per diem basis. The underfinancing pertains to all aspects of residential care. Many institutions have budgeted positions which are now vacant. On the basis of some rough calculations it is suggested that about 30% of all budgeted positions in residential facilities are now vacant. This can be partially explained by the fact that the attendant positions of many of our public institutions are at the level designated by our national government as poverty wages. Three thousand dollars per year will not provide personnel of high caliber. Since the cottage life personnel and the ward personnel constitute the backbone of any residential program, it should not be surprising to find that the program for rehabilitation is frequently seriously inadequate or lacking altogether.

Underfinancing contributes, of course, to the understaffing. Many residential facilities do not have full-time physicians on their staff. Physical therapists are frequently lacking altogether. Speech therapists may consist only of untrained individuals. Occupational therapists may be totally unknown. While the clients may be kept clean, they often have no programs for daily living other than the meaningless blare of a television set or the completely empty fenced-in court.

A few years ago Burton Blatt and his colleagues put out a book called "Christmas in Purgatory". In this book Blatt indicated pictorially the deplorable state of some residential facilities, depicting this in a most graphic fashion. Although criticized by some, I believe Blatt has performed a great and important service by pointing up this shocking problem. I have seen, for example, a man without legs condemned to walk on his stumps because he once ran away from the institution, got lost, froze his legs and had to have them amputated. Everyone was reluctant to provide him with rehabilitative services for fear that there might be a repetition of his behavior and, furthermore, it was a deserved punishment. There are places where patients sit naked surrounded by their excreta.

Overcrowding, understaffing and underfinancing are three of the important issues related to public facilities but there are others. Some of the others are in the realm of obsolete architecture and design. Upkeep has been poor so that lavatory and toilet facilities are nonfunctioning, food preparation cannot be carried out in the desired sanitary fashion, and heating systems may be unequal to the task having buildings either too cold or too hot. Lack of educational and vocational programming also contribute to the sorry state of our institutions. To top it off nonexistent community resources complete the picture, forcing many to remain in the institution because there is no place to go.

Many Americans have the impression that poor residential facilities are something which must be endured along with other evils of our times. This situation certainly need not be tolerated. One can visit several of the European countries, especially the Scandanavian countries to find imaginative and unusual programs of care. Along with others I have been impressed by finding residential facilities in Scandanavian countries which were located close to the population centers.

In Copenhagen I visited a facility, The Children's Hospital at Vangede, well within the city limits. Many of these facilities have no more than 150 to 200 people. Staff ratios would be 1:1 and the care provided exemplary. In addition the physical surroundings are attractive, abounding in bright colors. Fixtures and furnishings are attractively designed and not the clumsy prison industry furniture often found in this country and everything is meant to be of interest and to have appeal to those who must reside in a residential facility.

If one is to solve in some measure the problems of our overcrowded institutions, then corresponding attention must be given to community resources. It has been pointed out on many occasions that the galaxy of services needed should include day care centers, schools, diagnostic centers, vocational training centers, sheltered workshops, group living homes, etc., and the personnel to staff them. I would maintain that residential facilities will not be what we want them to be in the future unless efforts are made simultaneously to rectify the situation in the institution and in the community.

The President's Committee on Mental Retardation is deeply concerned about all of these issues. The Subcommittee on the State of the Nation was instructed to give serious study to this problem during the course of this year. As a consequence of this admonition, I have invited several American and European leaders to help us and, in turn, the American public, take a careful and thoughtful look at the plight of the nation's programs and facilities for the residential care of the retarded. These leaders have all agreed to contribute their thoughts and ideas in the form of chapters of a monograph which is now almost complete. Mindful of the complexity of the problem, the editors have not tried to provide an exhaustive treatise on residential care but rather to select some individuals who were known for their very great contribution to innovative thinking, planning and constructing of residential facilities. From these efforts some far reaching recommendations will be made to supply a blueprint for residential care in the future.

As one major effort towards accomplishing the objectives which are desired, massive reeducation is going to be required. There is nothing to be gained by hiding the fact that our residential facilities are in a deplorable state, their buildings crumbling, the staff overworked, underpaid and often undertrained and the programs available providing only minimal care and rehabilitation. Each state must develop an even greater public education effort to bring to the attention of the citizens this blot on our escutcheon. It should be the wish and desire to try to rehabilitate patients to the community rather than to segregate them. This reorientation in thinking will require considerable effort as public officials, administrators of institutions, professional people, and the lay public all come to understand that the physically handicapped and the mentally retarded do not need to be moved aside but rather should be a part of the ongoing programs of communities.

In addition, nursing homes, rest homes, and convalescent homes should all be part of the services available in the community. Even severely retarded individuals with extensive physical handicaps can be handled in the community. Great Britain some years ago pioneered with the idea that the physically handicapped as well as the person with other handicapping conditions can and should be maintained in the community, but to do this they developed a concept that even the most severe form of handicapping conditions which might require prolonged nursing care should be cared for in facilities in the community as part of a regular pediatric unit. Such services need not be separated, segregated and removed from society.

An attitude of helping should be inculcated into all of the helping professions; Mrs. Una Haynes, long associated with United Cerebral Palsy, has amply demonstrated the kind of things which can be done for the physically handicapped and the mentally retarded. Her type of enthusiasm will go a long way towards trying to promulgate far better ways of thinking about the mentally retarded. In brief, one should ask the question why cannot all patients be maintained in the community. Why should they be removed? Should not society aim towards trying to help where the situation of mental retardation or physical handicap has occurred? One does not say to the parent of a child with leukemia that he should be "put away" even though everyone recognizes that the child will ultimately die. Rather all forces are mobilized to help and to sustain the child in the community even though he may need periodic hospitalizations. Surely, the same approach should be used for the mentally retarded and the physically disabled.

The Foster Grandparent Program has been successful in helping to cope with the manpower problem. It takes a cognizance, of not only the needs of the retarded and the handicapped persons but also the elderly who similarly are looking for places in our society where they can be of help and assistance and so that they will not be thought of as misfits and people relegated to a shelf. The SWEAT program has been another device used successfully in trying to attract people, in this instance young people, to have some exposure to mental retardation thereby dispelling some of the fantasies they have had about the difficulties in working with the retarded and also giving them some knowledge about how rewarding such a career can be. But more is needed and much greater effort will be required if the manpower problem is to be solved.

Let me tell you briefly about a training program going on in Denmark. They have a three-year program which essentially is half practicum and half theoretical. Here, the students, many of them akin to the school drop-outs in this country, are recruited for these positions, subsidized during their period of training and then provided with good situations in which to work. Throughout the Scandanavian countries I have been greatly impressed by the numbers of young, eager, well informed men and women one finds in their institutions helping the retarded. At a school for cerebral palsied children in Gothenburg, Sweden, I had the opportunity of visiting one of the most delightful places to be seen anywhere. This happened to be a residential facility where things were so well developed that one could find a child who was ill from some other cause being carefully read to, rather than being left alone as is so frequently the case in our country.

Many of these young people in these Scandanavian institutions will drop out after three or four years of service so that the turnover is fairly great but there is another interesting side light to all of this. Many of these young people will go on to be parents themselves and having learned something about the handicapped as well as something about child development they will be in a better position to manage their own families. At any rate it can be noted that these ingenious training programs in the Scandanavian countries have come close to solving the personnel problems. This idea should be studied carefully by all of the states. Significantly new funds would need to be made available if it were to be implemented.

In thinking about solutions for residential care, one certainly must give thought to architecture and size. Many of you will be hearing from Dr. Gunnar Dybwad about the architectural barriers in residential facilities. Dr. Dybwad has become a world authority on this important problem. He and others would point out that if existing buildings are to be modified in order to make room for the clients, a loss of bed space is inevitable. The Scandanavian countries, again leading in the area of remodeling existing buildings, have pointed out from their ten to fifteen years of experience that it is absolutely necessary to plan on reducing the number of beds by half if the former construction had been along the general open ward variety. Consequently a facility that formerly housed 50 will now house only 25.

I realize that it is still considered controversial as to the desirability or not of having larger facilities of 1,000 or more. Many of our facilities are this size and some are now being constructed that will be of this size. The evidence is not convincing to suggest why large residential facilities need be built. The argument often runs that large facilities cost less to operate. I would suggest that this point has not been proven. Currently the President's Committee on Mental Retardation is in the process of making a study about what is known in reference to costs of running large versus small facilities. There seems to be some evidence that would suggest that small facilities of 150 to 250 can be operated and constructed at no more than the cost now being utilized in the larger residential facility and perhaps even at less cost. Cost analysis can be deceptive however, if one is not comparing like commodities. The study I have mentioned will, I believe, shed some important light on the matter of cost of operating these various facilities.

An additional point to be made about the size of an institution certainly relates to one's sense of human values. In today's world, where many of us become numbers on an IBM card, we all feel great reluctance to bid farewell to a more individualistic approach to the problems of human care. A return to small units whether in a university, a city, or a residential facility seems to be a matter of inceasing concern to many people. These human values must not be permitted to be overshadowed by too much architectural efficiency and the engineering consideration of locating buildings at the point closest to the steam plant. Surely we have lived with problems of regimentation for too long and must be ever on guard in all sectors lest we perpetuate this.

I realize that I have not said very much to be happy about. I have not told you how well we are doing in the matter of residential care in this country for any group of patients. I do not think that those of you in UCP, also concerned about residential facilities, should make every effort to join hands with your colleagues in the mental retardation movement to see what can be done to improve this deplorable situation. I would suggest that the efforts will need to be massive and I would further suggest that the reorientation of the community will be a crucial factor. Facilities close to where people live should be the watchword. At the same time we must attend to reconstructing our existing facilities, to improving the pay scale, to reducing the number of clients and to restructuring the mission of residential facilities in ways which return clients to the community.

# BETTER CARE FOR SEVERELY INVOLVED CEREBRAL PALSIED RESIDENTS OF STATE INSTITUTIONS--IT CAN BE DONE!

Una Haynes, R.N.

PRESENTED AT UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 23, 1968 Rice Hotel, Houston, Texas

Several factors appear to be involved in the rapidly increasing proportion of individuals who have cerebral palsy and related neurological impairments within the population groups now being served by state institutions for the retarded throughout the United States. While improvements in the creation, operation and expansion of community services for the retarded permit many families who previously requested residential care to now maintain their less severely handicapped family members at home. In addition, the more globally involved individuals are still excluded from the majority of these community programs. The more severely disabled also seriously tax family emotional, social and financial resources, leading families to request residential placement away from home. Advances within the scientific community enhance the survival of exceedingly vulnerable infants; and increase the longevity of those with severe and multiple handicaps. As a consequence, mentally retarded individuals with cerebral palsy and related impairments now constitute over 30% of the population groups in most multipurpose institutions. Some states appear to be moving in the direction of segregating these severely handicapped residents within specialized institutions. If this meant that there would be an increased patient-staff ratio, employment of highly qualified rehabilitation personnel and an architectural design calculated to foster mobility, there would be less reason for concern. Unfortunately, state appropriations do not reflect this point of view.

It is exceedingly important, however, to note that the personnel involved in both the multipurpose and the other "segregated" type institutions demonstrate vital concern and a serious effort to meet the needs of these multihandicapped residents. One example is that UCPA has already accepted invitations to conduct inservice education programs in over 50 of these facilities in 28 states. These slides illustrate some of the changes one sees on return visits to these institutions. The improvement is sometimes so vast that it is literally hard to believe these are actually the same patients.

Some United Cerebral Palsy affiliates on state and local levels have clearly demonstrated, by their cooperative efforts with institution personnel, that they really care about individuals with cerebral palsy. These affiliates clearly demonstrate that for United Cerebral Palsy it is not a case of "out of sight, out of mind."

This morning there will be a truly exciting session in the Brazos Room. Come and see how Barbara Campbell and Patricia McNelly have brought about these enormous improvements in their particular institutions. Come and hear Jim White tell you how United Cerebral Palsy has motivated, enhanced and rewarded these efforts in Wisconsin.

Come and see the truly inexpensive but innovative items of equipment.

Come and learn how children are measured for new wheel chair inserts; how these are made and fitted; how performance is evaluated before and after these new approaches.

I promise you a most interesting and rewarding experience to share with your colleagues on the home front.

Thousands of children and adults can benefit from your concern and attendance here today.

# CARE IN STATE INSTITUTIONS

Barbara Campbell
Director, Nursing Services
Warren G. Murray Children's Center, Centralia, Illinois

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 23, 1968 Rice Hotel, Houston, Texas

At the Warren G. Murray Children's Center in Centralia, Illinois, we have 700 moderately severe and profoundly retarded residents ranging in age from 6 to 21 years of age. There are 5 cottages each housing 100 ambulatory residents and two cottages each housing 100 nonambulatory residents. The cottages house 25 residents to each wing and within each of these 7 H-shaped cottages, there are facilities for the residents' living, sleeping, bathing, dining, and playing. There are separate areas for clothing, soiled laundry, beauty or barber facilities and classrooms. There is a medicine room, a Doctor's examining room and there are several offices. The hot and cold food carts are brought to the cottage kitchen and meals are served in the dining room. In other words, the cottage is home and the resident need not leave the cottage for any purpose other than to obtain a service offered either in the hospital building or the community building. Our goal, though, is to provide opportunity for new experiences and socialization whenever possible, off the cottage as well as on it.

The community building is just what it sounds like. Here, the residents have the experience of venturing out into a community-like atmosphere for classes, movies, church services, snack shop, etc. The hospital offers all of the clinical services associated with the treatment and prevention of illness. There is a Dental Lab, EEG, X-Ray, Clinical Laboratory, Outpatient Clinics and Physical Therapy, as well as Central Supply and Emergency Room. The Hospital wards have 24 beds for medical patients and 24 beds for surgical patients, plus 10 beds for isolation and 4 for intensive care or postanesthesia recovery in conjunction with the operating room.

Nursing services are responsible for the total care of the 2 cottages for the nonambulatory residents, and also the total care of the acutely-ill hospital patients. Nurses have an overall responsibility for a "visiting nurse" type of care in the 5 cottages housing ambulatory residents. Here the immunization program and a school nurse health care are most important.

Within the Warren G. Murray Children's Center there are three program areas: Units I, II and III. Units I and II are under the jurisdiction of Cottage Life while Unit III is Nursing Service. Unit I concerns 2 cottages, whose residents are being readied for semi-dependent life, which might include:

1. Conditional discharge to parents.

2. Wage placement
    a. Possibly a half-way house
    b. Community day work

3. Sheltered home placements.

Unit II concerns 3 cottages for residents who will likely always require sheltered-life programs. Unit III includes the 2 cottages for nonambulatory residents and also the acute hospital. The goals for nursing may be stated broadly as habilitation nursing care with emphasis on self-help skills and habit training. More specifically, I might mention that we have three levels of residents: For Level III the goals for the young adults and adolescents would include: Development of essential grooming skills, social skills, work skills, communicative skills and practical knowledge necessary to successful living in a partially dependent or fully dependent situation in the community. Practical knowledge also includes learning independent travel in a wheelchair and/or developing skills such as getting in and out of wheelchair unaided.

Level III - Children - Development of essential grooming skills, social skills, work skills, communicative skills and practical knowledge also includes learning independent travel in a wheelchair and/or developing skills such as getting in and out of wheelchair unaided.

Levels IV & V - Young Adults & Adolescents - Rehabilitation and/or extended nursing care including development of basic self-help, wheelchair, communicative and behavioral skills essential to a happy and adequate adjustment to life in a sheltered home or an institution.

Levels IV & V Children - Rehabilitation and/or extended nursing care including development of basic self-help and wheelchair skills, and habit training essential to adequate institutional adjustment.

Each of the three units at our center, whether under the direction of Cottage Life or Nursing Service, is set up in a very similar manner. For instance, in nursing services' Unit III, there is a unit director who is a supervising nurse. Then, in each cottage for the nonambulatory, there is a supervising RN in charge who is the cottage director. Her staff is made up of staff nurses, practical nurses, nursing assistants, activity aides, dietary aides, clothing aides, housekeeping aides, a barber and a beautician. There is also a unit professional team which includes the services and consultation of a doctor, chaplain, psychologist, special educator, social worker, speech and hearing therapist and activity therapist. This, in general, then is the overview of the Warren G. Murray Children's Center.

All nursing personnel need to be imbued with the knowledge that the retarded resident has his own individual worth and dignity. We must meet his basic needs of love and security by offering him as nearly as possible in our facility, a home with family and environment. One important step in this direction is our assignment of direct care personnel, not to a cottage or a building, but to a specific group of eight residents. This, then, becomes her group for which she is responsible and with which she is most involved. In each cottage, it is a matter of written record which employee has which group and who the relief persons are.

It is our belief that, while the best nursing care both updated and traditional is important in the widest sense of the word, such care is not an isolated end in itself. Uppermost in the minds of nursing personnel in an institution for the retarded must be the attainment of growth and developmental goals individualized for each resident. In essence, nursing services' philosophy might be summarized as ongoing search for each resident's maximal potential in health andwelfare.

Under the administrative and supervisory registered nurses, the staff nurses, practical nursings and nursing assistants share an overall responsibility for this comprehensive nursing care. These direct care personnel are charged with all of the usual tasks related to nursing care. In addition, they are involved in beginning teaching of language development, motor skills and basic self-help skills or habit training. Dispensing quantities of affection and simple experiences ranks high among their helpful activities, insofar as is possible, the nursing personnel fulfill the mother-father role, keeping in touch with all of the cottage residents, but being primarily responsible and involved with their assigned group of 8 residents.

An ongoing inservice training program is an essential and the agenda would not sound like that expected in a typical nursing situation because it would have to allow for the aforementioned situations. The training program might include normal growth and development; mental retardation including recent findings, classification and symptomatology;programs on feeding techniques and adaptive equipment, psychological approaches meeting the training needs of the mentally retarded; training by positive reinforcement; basic self-help skills; habit training and behavior shaping techniques. These inservice classes are under the general direction of the supervisor and staff nurses with guided participation at all levels of nursing personnel.

In the nonambulatory cottage, our daily routine is a program: every resident is dressed, put into an appropriate wheelchair or recliner chair and taken to the dining room for each meal. In addition to scheduled snack and nap time, each resident experiences his individual program depending upon his functional level. Variations range all the way from positioning on a mat, turns in a sitting box or standing box to trips to the community building for a snack-shop treat or a grounds pass enabling them to move about freely on the grounds. These same residents are involved in off-the-cottage work adjustment programs for 1 to 3 hours per week.

I think now with this overview of the Murray Center, we can look at nursing services' newest program, started late in 1966, which we call our wheelchair adaptive equipment. For a little background information, I would like to tell you that getting the children out of bed has been our policy from the day that our infirmary doors first opened in May, 1965. Back in those days, we had 2 sizes of wheelchairs - too big and too little. Nevertheless, the children got out of bed daily to be propped, folded, squeezed and tied into whatever contrivance we had - recliners, wheelchairs, stretchers and wagons. It was quite a parade, but somehow they got to the dining room and back. Now things are looking better; we have been fortunate in securing the right size wheelchair for each of our 200 nonambulatory residents. The only catch is that our feeding programs have been so successful that the kids are growing and gaining weight so they are outgrowing their wheelchairs. However, this is something that we are happy about and we are meeting the situation as best we can.

You can imagine that within an age range of 6-21 years, the residents are of many different sizes. Each resident is an individual with an individual problem and each problem is different. Our children are hypotonic, spastic, athetoid, hemiplegic, quadriplegic or a combination of these; while others have sclerosis or hydrocephalus, etc. I might add, too, that since all of our children here are at least 6 years old before they are admitted to our center, you can imagine that they are already plagued with progressive joint contractures, scoliosis, poor posture, poor balance, muscle waste and the like. So it is obvious that each of our nonambulatory residents requires a special piece of equipment appropriate for his or her needs. Previously, it was necessary to use restraints, seat belts, vests, shoulder straps and what have you to help these youngsters sit up in whatever kind of wheelchair we were able to have for them. In many ways this was actually a danger because invariably the restraints would work loose either allowing the child to fall or in some way restricting his respiration as he slid progressively down and out of the restraints. Particularly the athetoid children injure themselves easily, bumping shins, heels and elbows on various parts of chairs and foot rests. Thus, our goals for wheelchair adaptation were:

1. To provide a comfortable and therapeutic menas of transportation to the dining room and off the cottage.

2. To facilitate socialization, that is the child could focus on others in relation to himself and his surroundings.

3. To promote along comfort, improved posture, blocking of abnormal posturing reflexes, such as tonic neck reflexes, extensor thrust.

4. To encourage stimulation, that is the resident could see and focus attention, to participate, to reach out with his eyes and then with his hands.

5. To help solve medical and nursing problems, connected with feeding, aspiration and swallowing, hand chewing and gagging, as well as injuries due to bumping.

I would like now to share with you our "before and after" slides which really are self-explanatory. In the "before" series you will see that the residents were often unable to attain or maintain eye contact with anything or any one. The majority were far too busy trying to maintain their balance or trying to support themselves in the chairs. Ceilings, floors, knees or feet can hardly be classified as interesting or stimulating to anyone and particularly not to a retarded person.

In the "after" series you see youngsters comfortably postured with individualized support to back and feet. Many require special neck and head rests but already these muscles are being trained and strengthened to offer support with minimal help from devices. The lapboard affords postural assistance as well as a comfortable support for arms and hands. Extra padding can be placed to further protect constantly moving athetoids.

Even a self concept, an awareness of hands and the relationship of self to others is now more evident. We find that the youngster presents a more appealing appearance which definitely enhances his social acceptance.

At first, the direct care personnel thought to themselves, "Horrors! Five or six extra items of wooden puzzle will complicate my already tough job!" Now, the hue and cry is, "When do my kids get their chairs fixed?"

We obtained our information and enthusiasm in a singularly delightful manner. In April of 1966, we held a nursing seminar on cerebral palsy at our center. This was sponsored by United Cerebral Palsy of Illinois, Southern Illinois and South Central, Illinois, and we were most fortunate to have as special guest consultant - Mrs. B. Quincy Haynes, Associate Director and Nursing Consultant, Medical and Scientific Department, United Cerebral Palsy Associations, Inc., from New York. Another special consultant was Miss Anita Slominski, Clinic Director, Cerebral Palsy Center, Indiana University Medical Center. From these two persons, who gave us a wonderful lecture and demonstration on "Nursing, per se, in management of the cerebral palsy problem", we were well on our way. To Miss Slominski's Cerebral Palsy Clinic in Indianapolis, we sent two handymen for a week and two nurses for two days to learn the proper techniques in measuring, positioning and building wheelchairs. We found early that we needed a full-time carpenter, who was real carpenter, a cabinet maker who could devote full time to this project at our center, and we were fortunate in obtaining such a person about a year and a half ago. This carpenter also attended Indiana University Clinic to receive experience in constructing chairs and adaptive devices for the "stripped-down" or simplified wheelchair. Now, we have a very functional team - an RN and a carpenter who have been designing and constructing adaptive devices to fit individual children measured according to their own special requirements and needs. To date, 75 of our 200 wheelchairs have been so adapted, and already we are happily seeing improvements in socialization, readiness for learning and the blocking of abnormal posturing reflexes.

The circulatory, respiratory and digestive problems that used to plague these infirm residents have been notably reduced. With improved posture both swallowing and breathing have been aided, thus helping overcome tendencies to choke and aspirate. Poor posture and poor coordination are being replaced by better balance and the possibilities for more social stimulation such as improved attention, reaching and beginning of self-concept, self-help skills and the like. Thus, we are delighted that, through our wheelchair project, many of our infirm residents are significantly aided socially, physically and developmentally. We feel that it is a 100% worthwhile project and we are very grateful to the original authors of this idea at our center, Mrs. Haynes and Miss Slominski. We are pleased that we have been able to provide, especially the more severely handicapped residents, with such professionally designed pieces of equipment on the scale we have. We fully expect to continue building and maintaining such pieces of equipment, feeling that at this time this is a very worthwhile project.

# PROGRAMMED LEARNING AND VOLUNTEERS

## Research and Training Project in a State School

Victor Hinojosa, M.D.
Director, Volunteer Research and Training Project
Austin State School, Austin, Texas

One must find ways in which learning can be fun for the mentally retarded. The basic idea to a more pleasant, efficient and permanent learning occurs when the student proceeds through a course by a large number of small, easy-to-follow steps, on a one-to-one basis. The TMI-Grolier programs are used in the Volunteer Research and Training Project.

Both the instructor and the student benefit mutually due to the fact that the TMI-Grolier program is built on the basis of learning principles of recognized soundness. This program also provides the student with the feeling and the actual benefit of working on an individual basis by an instructor. This special attention always does wonders for the mentally retarded individual, and the rapport usually established is most impressive.

Since March of 1966 at the Austin State School a new project went into action. The title is "Use of Volunteers as Trainers of Retarded Children." The aims of it can be summarized by saying that through intensive training and supervision of volunteers, these can extend themselves into areas which were previously only held by highly trained staff personnel.

A group of seventeen volunteers interested in the education, especially in the instruction phase of it, were chosen by the director of the volunteer project to participate in the institutes of programmed instruction coordinated by the project. The instruction of the material was given by a staff psychologist who had previously been active doing this type of teaching on a very limited scale.

Since June 14, 1966, three workshops (2 sessions of 4 hours each) have been held with fourteen volunteers. Intensive training was the purpose of these institutes. Individual instruction has been given to three volunteers. Since September 1966, four (2 hours each) discussion periods have been held. During this time, students, methods, progress and questions and answers were freely discussed.

The courses which the volunteers learned to teach under the programmed instruction are spelling, arithmetic and reading. This material covers through the third grade level.

The spelling begins by the teaching of vowel-consonant discrimination, with emphasis on an exhaustive treatment of vowel sounds. It also teaches many new words, such as week-days and names of months. The words taught in the TMI-Grolier course are not determined by their alleged difficulty, but, among other things. by whether they are likely to be in the student's vocabulary. The course is made up of 2990 frames and the student is required to spell 400 complete words and parts of many more.

The areas covered in the arithmetic course are addition, subtraction, multiplication and division equations that only contain numerals 10 and smaller. Verbalization processes are introduced early. Action cartoons are also used to illustrate the principles of arithmetic.

The steps in Reading for Meaning course has 1702 frames employing 1000 pictures. The student is led in easy steps through tasks such as selecting pictures which go together or finding a part that is missing. He then proceeds to selecting a word, in easy steps, which goes with a given picture or finding a picture which goes with a given word. Sentences are later introduced which contain a new word with the rest being words established at the beginning of the course.

One of the volunteers was chosen to undergo instruction in the administration of pre-and post-testing of all students who are referred to the Volunteer Project for Programmed Instruction. These psychological tests are the Peabody, California Arithmetic, Teaching Material Incorporated Reading Vocabulary, Wide Range Achievement and Spelling. These tests will determine the resident's eligibility into programmed instruction. After the termination of the course another test is administered to determine the progress made.

TABLE

Number of Students, Sessions and Hours in
TMI-Grolier Programmed Instruction

| Month | Students Receiving Programmed Instruction | Number of Sessions of Programmed Instruction | Number of Hours of Programmed Instruction | Number of Hours of Testing |
|---|---|---|---|---|
| 1966 | | | | |
| March | 4 | 12 | 4.6 | -- |
| April | 5 | 13 | 5.4 | -- |
| May | 5 | 13 | 5.8 | -- |
| June | 12 | 44 | 22.5 | -- |
| July | 13 | 87 | 42.9 | 23 |
| August | 17 | 63 | 32.2 | 45 |
| September | 27 | 142 | 62.3 | 9 |
| October | 36 | 170 | 83.0 | 6 |
| November | 32 | 161 | 76.9 | 6 |
| December | 30 | 124 | 58.5 | 3 |
| 1967 | | | | |
| January | 28 | 136 | 62.1 | 2 |
| February | 35 | 164 | 79.8 | 3 |
| March | 35 | 231 | 109.7 | 4 |
| April | 34 | 184 | 86.2 | 21 |
| May | 32 | 184 | 85.1 | 6 |
| June | 23 | 77 | 34.7 | 4 |

| Month | Students Receiving Programmed Instruction | Number of Sessions of Programmed Instruction | Number of Hours of Programmed Instruction | Number of Hours of Testing |
|---|---|---|---|---|
| TOTALS: | | 1,805 | 851.7 | 132 |

Note: 60 students have participated.

CONCLUSION:

In the sixteen months that programmed instruction has been undertaken by seventeen volunteers (9 housewives and 8 college students) in this project, a total of 60 mental retardates have profited from the individual instruction administered in the various courses. Each resident has received an average of 30 sessions and 14.2 hours.

40 have/or are receiving the reading program.

16 have finished the reading program.

26 have/or are receiving the addition and subtraction program.

9 have finished the addition and subtraction program.

19 have/or are receiving the multiplication and division program.

3 have finished the multiplication and division program.

10 have enrolled in the spelling course.

1 has finished the spelling course. (Due to extended furlough he has not been post-tested.)

6 have been pre-tested and found to have mastered academic material at a higher level than currently used in our project.

4 have been pre-tested and found that their level of language comprehension was so low that they would have had great difficulty following the instruction of volunteer tutors.

The post-scores were at least doubled over the pre-scores with the exception of the addition program. Possibly, the reason for not doubling in the latter is that most of the residents participating in the program have a basic concept of addition. (It will be noted that the pre-score on this program was the highest.)

Programmed learning is an experiment in education which provides the resident with material that has been scrutinized carefully and which permits him to make progress at his own pace -- either as slowly or as rapidly as he can go -- in our case, it has provided the volunteer to delve into the special educational field of mental retardation and prove that, no matter what his preparation might be, he can perform a most adequate and laudable service.

## SMALL BUSINESS ENTERPRISES PROGRAM - A UNIQUE EXPERIMENT

Alfred P. Miller
Assistant Director
Federation Employment and Guidance Service
formerly with UCP of New York City

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE

United Cerebral Palsy of New York City has been conducting this rather unique experiment in vocational rehabilitation for the cerebral palsied over the past two years.

The program is known as "Small Business Enterprises" and has an initial purpose of providing training for the cerebral palsied in small business operations. Upon completion of a one year course of training, the cerebral palsied graduate is offered one of the following opportunities: 1] set up in an independent business in cooperation with his Division of Vocational Rehabilitation counselor; 2] placed in a job in competitive industry by the placement counselor; 3] enrolled in a long-term (sheltered) work program with United Cerebral Palsy of New York City, Inc.; 4] offered a staff assignment as a trainer with the Small Business Enterprises Program.

The original vehicle for training in small business retail operations was a vending stand located in one building of a six-building middle-income cooperative housing project in the Bronx, New York, known as Concourse Village. The space for the vending stand was arranged for, rent free, through the generous cooperation of Mr. Jerome Belson of the Amalgamated Meat Cutters and Butcher Workmen of North America, AFL-CIO. Mr. Belson and members of his union are the sponsors of the Concourse Village Housing Project. An Extension and Improvement Grant provided jointly by the Vocational Rehabilitation Administration of the Department of Health, Education and Welfare and the New York State Division of Vocational Rehabilitation provided the initial funds for construction and staffing of the project.

The program was designed to explore the potential of adults with cerebral palsy for the operation of retail businesses. One of the major questions at the outset was what reaction the tenant cooperators, i.e. the potential customers, at Concourse Village would have in dealing with severely handicapped adults in across-the-counter retail sales situations. Another major problem to be explored was whether the cerebral palsied adult could serve the public with the necessary speed and accuracy the consumer demands and whether he would be capable of handling coins, stocking the stands, carrying merchandise, packaging merchandise, and other functions that are necessary in retail sales operation.

Currently, six vending stands, one in each of the six buildings at Concourse Village, plus a vending stand located at UCP's Main Offices at 141 East 40th Street in New York City, are now in operation. There are 14 cerebral palsied graduates of the Small Business Enterprises Program who are awaiting placement as independent stand operators at housing developments other than the Central Training Facility at Concourse

Village. This brought about the need for a second stage in the Small Business Enterprises Program, i.e., construction of vending stands and placement of graduates of the program in other housing cooperatives throughout New York City.

During the course of the program, certain logical additions were made to the original concept of rehabilitating and training individuals for retail sales. It was noted that there was need of a stock and distribution program in order to train clients in all functions necessary to supply the various stands. It was also obvious that a program of porter training could be incorporated into the original program.

Many requests had come in from tenant cooperators for various services for the tenants of the cooperative housing development; for example, a valet service in which the tenant would deposit his clothing at the stand in the morning when going to work and pick it up cleaned and pressed upon returning from work in the evening. The cleaning would be contracted for at a local dry cleaning store or dry cleaning plant in the community. Another service request was for a dog-walking program, since in many families both the husband and wife worked and preferred to have their dog walked once a day while they were at work. Still another request was for a laundry service whereby the laundry would be picked up from the tenant at his apartment, put through the washing and drying machines in the building and delivered back to the tenant's apartment for a service fee. A porter cleaning service to clean tenant's apartments in lieu of a severe maid shortage in New York City was also suggested. Gradually, the concept of an over-all "Shopping Center" approach for services to a housing cooperative began to take shape.

One of the benefits of this type of program is that it enables screening and evaluation processes to be much less selective of the clients who may enter the training program. If a client is not capable of retail sales, he may then be evaluated for any of the following programs; stock and distribution, porter training, dog walking, laundry service, valet service, soda and newspaper delivery, or any one of a number of service occupations. This enables United Cerebral Palsy of New York City to evaluate many more clients in a broader array of service skills than was originally anticipated.

In addition, having the program located in various housing developments in all parts of the city, makes it geographically possible to service clients who may be unable to travel distances to one central training location.

The new name of the Small Business Enterprises Program, encompassing both the retail sales training and the services training, will be known as the "Metropolitan Area Sales and Service Program."

Offers of placement in competitive employment for graduates of the stock and distribution program, have been forthcoming. The Small Business Enterprises Program has been fortunate in receiving tremendous cooperation from private industry who have become involved through the normal business of the program, such as: the purchase of magazines, newspapers, toys, drugs and sundries, tobacco, candy, ice cream, and any one of 250 items which each of the stands offers for sale.

Every aspect of the program, both sales and service, is based on real work and thus produces an income enabling the program to pay the clients in training a training allowance on a gradually increasing scale and the graduates of the program a regular minimum wage, plus increments and fringe benefits with the opportunity to become independent stand operators and retaining most of the income at the stands they themselves operate.

The initial phase of the program consists of a screening, followed by a six-week period of evaluation. During this evaluation, the client spends approximately two weeks at the main offices in New York City receiving a battery of written tests, and work samples, plus intensive counseling interviews. He then spends two weeks at the Small Business Enterprises Program at Concourse Village and two weeks at the Graphic Arts Training Workshop. At the end of this six-week period, representatives of the evaluation staff at the main office and of the staffs of the Graphic Arts Training Workshop and the Small Business Enterprises Program conduct a case conference with the Division of Vocational Rehabilitation's rehabilitation counselor to discuss which area of training, if any, the client should be referred to.

All cases referred to the project are represented by a counselor from the Division of Vocational Rehabilitation. The eligibility criteria for the project are that: 1] the primary diagnosis be cerebral palsy; 2] the client be at least 18 years of age; 2] the client have minimum intellectual functioning not below the dull-normal range; except, in certain cases showing unusual potential; and 4] there be no precluding emotional disorder.

The structure of the program constitutes four primary or major phases: 1] Diagnostic vocational evaluation of six weeks; 2] Personal adjustment training -- 20 weeks; 3] Employment training -- 20 weeks; and 4] Placement exploration and follow-up -- 6 weeks.

In addition to these major phases, there are built into the program minor or subphases within each of the major phases as follows:

1. Orientation and observation phase of 2weeks.

2. Operation of a stand under full staff and continuous staff supervision, from 6-12 weeks.

3. Assignment to stands under supervision of an employee graduate of the program and limited supervision of staff on a graduated scale starting with one eight hour work shift per week and building up to five eight hour shifts per week. This phase lasts from 10-16 weeks.

4. Assignment to a stand with responsibility for the operation of that stand resting with the client under limited supervision of client-employee graduates, starting with one eight hour shift per week and gradually building up to five eight hour shifts per week. This phase lasts from 12-16 weeks.

5. The final and placement phase of the program, which lasts for six weeks, is conducted in the following manner: a) A client is given special training for a particular type of business which has been chosen for him through the cooperative efforts of the Small Business Enterprises staff, including the rehabilitation and placement counselors and the DVR counselor, in conjunction with his own desires and abilities. b] A client is given intensive supportive counseling to prepare him for the major step he is about to take. c] A client is given additional specialized training in record keeping. d] a client is teamed up with his prospective team-mate who will be his partner in the particular business set up for him.

The population referred for training during the eighteen months of the program numbered 36, of whom 30 were accepted for training. This group consisted of 25 males and 5 females, with an age range of 18 to 46. The median age was 33. 25 were diagnosed as cerebral palsy, of whom 11 were himplegic, the other 10 having some involvement in all limbs. Of the ten noncerebral palsied, one had Eale's disease, one Marfan's Syndrome, one had visual limitations from lye burns of the eye, and two were retarded. The range of IQ, as measured by the WAIS, was 59 to 120, with a mean IQ of 79. Seventeen were high school graduates; 10 had some high school; two were elementary school graduates, one had some elementary school. Eighteen had some work history; in 6 cases the experience was in a workshop.

Of the 30 who started training:

14 completed training
13 are still in training
and 3 dropped out.

Six clients who were referred for the program did not start training. One preferred other training, one found the traveling too difficult, and four were too physically impaired to be considered trainable for competitive placement as operators of small business enterprises. The principal condition that rules out chances for those not accept was athetosis. This condition makes it extremely difficult to handle coins deftly or to move quickly in providing customers with requested merchandise. In a pressured situation, such as during the morning rush hours, this disability can prove very handicapping.

## Findings

1. A total of 60 clients were accepted by the vocational department of United Cerebral Palsy of New York City, Inc. for evaluation. Of this number, 37 were referred to the Small Business Enterprises Program for evaluation; 30 were accepted for the program; 7 were found either not suitable for the program, or, as a result of a case conference with a Division of Vocational Rehabilitation Counselor, were referred to other programs within the agency.

2. The following table shows the current status and disposition of the 30 clients accepted for training in all subdivisions of the Small Business Enterprises Program.

Table 4. 1

| Current Status and Disposition (N-30) | |
|---|---|
| Retail Sales Trainees | 12 |
| Stock & Distribution Trainees | 5 |
| Porter Trainees | 2 |
| Retail Sales Graduate Employees | 8 |
| Dropped out of Program | 3 |

Of 23 males and 7 females, some of the findings of Small Business Enterprises Program observed to date are as follows:

1. It was found that, in general, the younger the client the less rigid the personality, as demonstrated by greater acceptance of supervision, criticism and instruction. Trainers encountered a lesser degree of frustration, cynicism, and a chip-on-the-shoulder attitude than among the older group. The older clients showed less patience regarding the length of time necessary to train and prepare them for graduation from program; the younger clients were more acceptant of the one year required to complete the program. There was no noticeable distinction between male and female clients.

2. Although a degree of hesitancy and tenseness was observed on the part of customers, i.e., tenant cooperators, during the first two or three days of exposure to our catastrophically disabled population, it was noted that within a period of approximately a week to ten days, the customers seemed to no longer be aware of the client's disability. Customer reaction was focused on the quality of service rendered to them rather than the degree of disability of the clients.

3. A greater degree of client motivation was demonstrated during the course of this project. This was evidenced in various ways. During snowstorms last winter, when this agency and many industries closed early to allow employees to return home safely, the clients in this project, when offered a similar opportunity to leave early, refused on the grounds that if they closed their stands there would be

a subsequent loss of business and customer satisfaction. Many of them stated that they felt toward the program the same way they would toward their own businesses, and since they would not close their own business during snowstorms, they likewise were reluctant to do so with the vending stands operated by the program. In addition, clients almost invariably reported on time to the program and their assigned tasks during the most inclement weather.

4. Since many of our clients received services in other rehabilitation programs in the past which have failed to result in a successful rehabilitation and placement, they arrive with a certain degree of cynicism and frustration. Hence, when they are originally interviewed by the program's rehabilitation counselor and are told the many ways in which they can benefit from the program, i.e., overcome the disabling limitations which prevent them from becoming a productive, useful member of the community, they tend to discount what the counselor is saying to the degree that the counselor's credibility is questioned. It must be noted that many of the clients have previously been told by counselors in other programs that they will be trained and offered supportive counseling, social service aid, etc. so that at the end of a program they would be able to earn a living, and take their place as productive members of the community. The facts of the matter are that these promised outcomes did not come to fruition, either because the counselor left the program or, for one reason or another, no placement or a temporary placement resulted. It was found that counselor credibility was reinforced in the Small Businesses Enterprises Program in the following manner. After the initial orientation interview at Concourse Village in the Bronx, a client is given the opportunity to see for himself, in the most pragmatic way, a handicapped individual, in many cases more severely handicapped than himself, who has successfully completed the program and is now fully employed, receiving a regular wage with full responsibilities for the operation of a vending stand. The client, usually after lengthy person conversations with the client-employee then returns for a follow-up session with the rehabilitation counselor. At this point, counselor credibility is no longer doubted and the client, with new motivation and enthusiasm, is now prepared to work with the counselor towards eventual successful rehabilitation.

5. Many clients who have taken part in the program have travelled from outlying areas within New York City, some of whom have had to spend three or four hours per day in transit. The program staff have been unable to service a great number of clients who were unable or unwilling to undertake such extensive travel. Many clients who were ambivalent regarding transportation at the time of referral, later overcame their objections, became increasingly motivated and involved in the program.

And last, but of extreme importance, it became apparent that cerebral palsied graduates of the program would require continuous services even as independent businessmen -- these include centralized purchasing, distribution and bookkeeping, and field representative management services on a periodic basis. The agency would also undertake to provide continued supportive counseling, medical and social casework services where and when required.

United Cerebral Palsy of New York City, Inc.'s current expansion into Metropolitan Area Sales and Service (MASS) will now enable the agency to service clients in outlying areas of the city and to offer the required services of central bookkeeping and central purchasing from the various "independent" stand operators.

The MASS phase of the program will enable the United Cerebral Palsy of New York City, Inc. to proceed on the continuum of rehabilitating the cerebral palsied to the highest possible level. Not being satisfied to consider its graduates as full employees earning a regular wage and fringe benefits, they wish to aid them in reaching the still higher level they are capable of attaining, i.e., independent businessmen (stand operators) or independent service contractors at a housing development. They will, of course, continue to supply essential business management and professional services to all of their graduates on a lifetime basis since the agency considers rehabilitation of the cerebral palsied a lifetime obligation (on the continuum of decreasing services the client may require).

United Cerebral Palsy of New York City, Inc. will make available a 15 minute color sound film of the Small Business Enterprises Program along with copies of a report on this project to UCP affiliates who express interest in this program and its possible utilization in their respective areas of service to the cerebral palsied.

Mr. David Miller, Chairman of the Publishers Planning Committee and Vice President of Reese Publishing, Inc. (no relation to myself) will discuss the special relationship developed between the publishing industry he represents and United Cerebral Palsy of New York City's Small Business Enterprises Program. He and his group have played a vital part in the success of this program.

# PBAA NEWSSTAND EXPANSION

David Miller
Vice President, Reese Publishing Co.
Chairman, Planning Committee, Periodical and Book Publishers Assn., New York, N.Y.

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 23, 1968 Rice Hotel, Houston, Texas

The Periodical and Book Publishers Association is a group of twenty-two publishers who have one thing in common. Their common denominator is the same fact that is universal to all wholesalers; that is that they make their livelihood from newsstand sales and newsstand sales only. The PBAA publishers sell more than 140 million periodicals and books on newsstands annually.

The PBAA program that I wish to tell you about today is Newsstand Expansion. However, the difference between this presentation and the hundred prior speeches that you have heard on this subject is that we have a program that WORKS. Not just an idea. We have added newsstands, a small number to date, but we plan to add 50,000 more across the country.

The month of November, 1967 was statistical history to the United States. The statisticians tell us that sometime that month, we were to hit the 200 million population mark. They also tell us that in the last 17 years, 50 million Americans, a 33% population growth has been added to this country.

This is amazing. But what is even more amazing are our statistics, the publishing industry statistics. In these same 17 years, while population has grown 33%, our outlets to service this population have decreased by 10% or more. This could indicate that 50 million people are not daily exposed to a newsstand. This is hardly the way for an industry that performs two distribution miracles each week, to compete with T.V., radios, movies, and, of course, subscriptions. I mention T.V., radio, movies because whether we like it or will admit it, we do compete with them for the leisure time and dollar that is available. I mention subscriptions because no one in this room makes a nickle from them. And, in fact, they are our single largest competitor for the leisure time and dollar essential to our survival.

There is no doubt that some people will pin my ears back shouting about the enormous gains in supermarkets and chain stores. They may forget to mention, conveniently, the arithmetic of this progress. The conversion of 60,000 outlets handling 100 titles each to 40,000 outlets handling 40 titles each. But, is thisimportant? The subscription sellers do not seem to mind. It is probably only important if we want to have a newsstand magazine business ten years from today. And, at the risk of being boring, considering the continually rising costs of manufacturing circulating and distributing publications, it is most possible that continuing decline of outlets could destroy this industry in the next ten years. I am not saying that we do not want these supermarket and chain store outlets. On the contrary, they are a most valuable piece of business. However, they do put the "neighborhood dealer" (and I put the words neighborhood dealer in quotes) out of business. The total newsstand sale in the community drops. And, in many instances, it drops not only for the publications that lose their neighborhood distribution, but also for the publications that continue with representation. Even though total traffic to the new outlets may be 20 times greater than traffic to the former "neighborhood dealer", the actual traffic to the magazine rack may be cut in half for several reasons:

1. These outlets are not usually within walking distance of home. Therefore, a person desiring a magazine to read at select times finds it easier to switch on T.V. than to get into the family car and drive three quarters of a mile or more.

2. Most racks in these markets are located in the low traffic areas of the store.

People go to supermarkets for an entirely unrelated purpose as regards our industry. As the ladies in our audience can attest, a shopping cart loaded with apples, soap powder, cereal (and maybe a few screaming kids as well) is hardly the stimulous for purchasing a periodical.

We would all surely agree that this trend of open an outlet, close an outlet, is not progress in sales or merchandising. Ladies and gentlemen, THINK!!! Think of the smaller numbers of selections available at our new outlets, the poor locations given to the racks in these new outlets, of the ever increasing travel time necessary to reach a magazine stand. Think of these things and ask yourself the question: are we, as wholesalers, national distributors and publishers beginning to bore and alienate our customers or, worse still, are we newsstand people creating a marketing pattern that will encourage the further growth of subscription sales? Up to this point, I admit to you, I have talked about the easy part. Anyone can and many have presented the problems, real and potential of our industry. However, this time we can also tell you about a program now very much in the works, to correct the diminishing newsstand situation. I would like to present this problem to you now. First, the question, why do potential newsstands remain empty? Three basic reasons:

1. Personnel to operate - this industry has been unable to find 100,000 additional people who are willing to work 60 hours a week to make $90.00. Yet, this is what it takes to run an average newsstand.

2. Cost to set-up - this industry has been unable to find 100,000 people who are willing to invest two or three thousand dollars to set up a newsstand to make $90.00 a week.

3. Locations - this industry cannot reverse the course of suburban growth and the changes that it brings with it. The former "normal" locations to sell our product still exist, but it is clear that a new formula for placement of outlets is needed.

For the past several months, I have been working with a group of people, not all of them members of this industry, to solve these three problems. Some of the group are Richard Browne of P.D.C., Al Miller and Leo Meyer of United Cerebral Palsy, Dr. Salvatore DiMichael, Bob O'Connell, Norman Subotnik of the U.S. Dept. of Health Education and Welfare, Marion

Martin, Louis Salzman of the New York State D.V.R. and Stanley Goldberg, Bronx County News Co. The solutions we have developed are:

1. Personnel - 100,000 persons who suffer from cerebral palsy, polio, epilepsy, cardiac, dystrophy, T.B. and other crippling diseases that afflict millions of the less fortunate of our fellow human beings. These persons can work and need work. We can combine in our industry the opportunity to increase our business and provide an unprecedented community service to the afflicted.

I can tell you now that the toughest of you will feel a tug of compassion and pride when you see young people crippled by disease sell magazines, paperbacks and comics from newsstands as we have.

2. Costs - the welfare and rehabilitation programs of the state and Federal governments are in a constant search for job opportunities for the disabled. These programs provide dollars for living expenses, training and the locating of employment opportunities and our business know-how to use the monies to set up small business opportunities and our business know-how to use the monies to set up small business enterprises incorporating newsstands into their design.

3. Locations - our program encompasses the reopening of many former locations. In addition, locations such as multi-story residential apartment buildings, garden apartment complexes, chain restaurants, shopping centers of all sizes, gasoline stations, garages, parking lots, office buildings, schools and, most important, mobile retail stands are planned.

Time does not permit to explore all of these in detail. However, let me tell you of our first test. Six stands have been in full operation for the past several months in the Bronx. They are located in the basements of multiple story apartment buildings. However, their design would also be practical for garden apartment complexes. The stands handle magazines, paperbacks, comics, newspapers, tobacco products, drug sundries, greeting cards, candy, soda, packaged bakery goods, etc. The buildings are new and about 70% occupied. Each stand services an average of 200 families. The stands are operated by disabled persons trained by the Small Business Enterprises Program of United Cerebral Palsy of New York City. The funds to set up the stands came through a combined New York State and Federal Government grant. The locations were given rent free by the Ammalgamated Meat Cutters Union. We have since contacted other landlords and have been offered more than 90 additional rent free locations for our test program.

Now, for the numbers. And these numbers should be of prime significance to every wholesaler.

First, in the last seven months, the combined billing to the six stands for magazines, paperbacks and comics has been slightly over $8,500. The stand operators estimate their returns to the wholesaler have averaged slightly under 25%. Second, the six stands are serviced by one delivery, one invoice, one return bundle and is paid promptly by one check. Third, the stands are open from 7:30 A.M. to 7:30 P.M., seven days a week. This makes it possible for the entire family to purchase there. Actually, 30% of the newsstand volume is currently purchased by men. We believe that the figures prove that newsstands can be opened successfully in a multitude of locations that this industry does not now cover. The program has been presented to personnel of the Federal, state and city welfare and rehabilitation offices. Their reception to the plan has been excellent to date.

Now for the future. The New York City area has been surveyed and we note that there are 630 additional newsstand locations available. Many of these locations in high traffic areas will sell periodicals for the first time in the history of our industry. We are expanding into New York State. Our next city to test in will be Buffalo. This is a city that is long and wide like most West Coast cities, rather than high like New York City. In Buffalo, we look to solve the problems of widely spread populations and to place our first newsstands on wheels.
In addition, from Portland, I go to San Francisco for a meeting tomorrow with representatives from the Department of Health, Education and Welfare. We will then begin the first steps necessary to set up training and test newsstands in the states of California, Washington and Oregon. Our goal is by 1970 to be working in every state with this program and to approach our Canadian wholesaler friends for the possibility of a similar program there. We believe our experience shows that people want to buy our products. Particularly if we make them more conveniently available.
Our experience also shows that a full line newsstand per 1,000 population is possible and profitable. This is the final result that we look for. However, we need your help. Several national distributors have offered and have made personnel available to us. We thank them. We also need wholesaler help. We need your ideas, criticism, experience and knowledge of the area you service. We must know the traffic patterns of your communities sothat we can attempt to solve them NOW as we test more areas. We are also interested in the licensing laws for outside stands in your area. Our search for locations is just beginning. The mistakes that we will make, we are willing to work to correct. You can save us from many of these.

We believe 50,000 newsstands can be added in the next five years. Our combined efforts can make this belief a reality.

Please write us, call us, talk to us - so that we may better serve the newsstand publishing industry from which we make our living.

# REHABILITATION SERVICES FOR THE HANDICAPPED

Russell J. N. Dean
Director, Washington Consulting Service

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 22, 1968 Rice Hotel, Houston, Texas

I deeply appreciate this invitation to join my many friends in the United Cerebral Palsy Associations for this Annual Conference. It has been my pleasure over the years to watch UPA and its affiliates all across the land grow into the kind of vital national organization it is today.

I would like to make a few general observations about legislation in Washington in the health and related fields and particularly pertaining to the handicapped.

For those of us who have watched the affairs of handicapped people for many years from a place in Washington, the situation has changed radically. Only a few years ago, anyone concerned with legislation for the handicapped needed to look in only a couple of places. One of these was the Vocational Rehabilitation Act, which as you know concerns itself solely with the affairs of handicapped people. The other was the Crippled Children's program of the Children's Bureau. In the late 1950's, another point of reference became important the disability provisions of the Social Security Act.

But, in the 1960's, this country finally became convinced that most agencies concerned with people should be concerned with handicapped people. More importantly, there was a realization that the fields of health, welfare, employment, education, training, and several others needed to have a clear statutory base for mounting programs designed to really get at the problems of handicapped men, women and children.

So today, any person who is interested in following the programs or legislative proposals affecting handicapped people must give attention to many agencies of government - the Department of Health, Education and Welfare and particularly its Offices of Education, Social and Rehabilitation Service, Public Health Service and the Social Security Administration.

He finds himself working with laws and legislation of the Department of Labor and its Manpower Development and Training Program, its Employment Service, its Wage and Hour Division and other elements.

He must concern himself with the work of the Veteran's Administration, the Armed Forces, the President's Committee on Employment of the Handicapped, the U. S. Civil Service Commission and several other agencies of government.

In other words, we are finally entering that long sought period when many agencies of the Federal Government are building specific programs, written into law, into their operating objectives and programs.

So as we move into this legislative year with the Congress, we do it against a background of remarkable legislative achievements in the last four years. This means that many of the bench-mark programs are already on the books.

Thus, 1968 is not going to be an historic year in legislation affecting the health field or work for handicapped people. However, it will be a very busy year, partly because of the volume of legislation partly because the Congress will adjourn early in this election year, and partly because the health legislation this year has gotten off to such a slow start.

The President's Health Message--which always is the key to the launching of an annual legislative program in that field was delayed this year for more than a month. As a result, many of the bills did not get to Congress until the first week in March. Hearings on one of these, the Health Manpower Act of 1968, began only this week, and the other major proposals are yet to be scheduled for hearings.

One bill in which you will have a great interest - the Child Health Bill - has gone to Congress but, at the moment, has not yet been introduced. You may recall that the President particularly stressed this year the need to mount an aggressive new attack on the health problems of mothers and children, especially to make certain that the child has complete health service and protection from the prenatal period through the first year of life. If this nation can ever fully realize this aim in daily practice, then we will have taken a giant step toward controlling the problem of cerebral palsy.

At this rather late date, the 1968 Amendments to the Vocational Rehabilitation Act have not yet been sent to Congress. This is a rather special year for these programs, since practically all the present authorities in law will expire this coming June 30, except for the basic program of grants to state rehabilitation agencies. Thus, the committee in Congress has only about three months remaining in which to schedule hearings and move a bill through the difficult legislative process in both houses.

Along with this, the committees will want to decide whether any program changes should be made this year as a result of the experience gained under the Vocational Rehabilitation Amendments of 1965. During that three year period, appropriations have risen from about $150 million to around a half billion dollars, and the committees will want to look at the results. I personally think they will be pleased with what they see.

Recently, the chairman of the House Select Subcommittee on Education, Mr. Daniels of New Jersey introduced his own Bill, H.R. 15827, to amend the Vocational Rehabilitation Act. Since he will handle rehabilitation legislation, both his bill and the Administration bill will be seriously considered this year. The two bills probably will not be far apart.

Regardless of the outcome of this and other legislation, there is one thing we can be thankful for: we won't have to wait till Christmas to get the results this year, for Congress will be adjourning as early as possible to attend to election business.

Mr. Chairman, my thanks to you and to your associates throughout the UCPA for inviting me here today. I believe you know I am deeply interested in the important work you are doing, that I will give my help and support in any way I can.

REMARKS BY
WILLIAM M. USDANE, PH.D.
Chief, Research and Demonstration Grants
Office of Research & Demonstrations, Social & Rehabilitation Service
Department of Health, Education & Welfare, Washington, D.C.

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 22, 1968 Rice Hotel, Houston, Texas

First - congratulations are in order to UCP on their five year plan of community service programming and their series of regional "Hearings" similar to the legislative ones of HEW and other governmental agencies. Testifying before Congressional Committees is part of the warp and woof of Washington bureaucrats, and it keeps government agencies constantly on the alert focusing on the future. Your theme of Focus on the Future is indeed an excellent one and brings to mind what Arnold Toynbee, emminent historian, has written about the 20th Century. He said that this century will be remembered as an age in which human society dared to think of the welfare of the whole human race as a practicable objective. And for the cerebral palsied infant, the high risk mothers, the child, the adolescent, the adult and the aged, your "Hearings" - your Focus on the Future - your constant programming and reprogramming will held us achieve that practicable objective in this century.

Second - Let us go immediately to recommended areas and specific programs wherein government and UCP should be working together and suggest specific areas for action by UCP. Let me tell you about a recent 11 minute film. This brief color film followed the experiences of the deaf who brought their National Repertory Theatre of the Deaf to the Rodman Job Corps Training Center recently, one of four to be closed by the Office of Economic Opportunity in New Bedford, Mass. This repertory group of deaf performs plays, musical comedies ( if, you will), poetry readings and was sold out 2 weeks in advance at the Vivian Beaumont Theatre in New York's Lincoln Center.

The impact of the deaf group upon these unemployed teenage-to-27, primarily nonwhite, groups was phenomenal. The camera constantly focused on their faces as they recognized the accomplishment and achievement of people who could not hear at all - who had little, if any, speech - but who were clearly able to communicate on a high, artistic, stunning level. The job corps boys verbalized their feelings full face to the camera. "They're more handicapped than we! I'd like to help and work with the handicapped - you know" said one - wide eyed and excited - "They can't talk, but they really can - they can't hear, but - man - they really can!"

But to the point - the cerebral palsied individual can be a part of modifying the hopes and goals of a class of people not accustomed to having a share in the shape of their destiny. The poverty groups in ghetto, inner city areas, have stopped responding to unconsistent, nonmeaningful, short lived concern for any focus on their future. Now, can we combine in store front settings within these poverty settings, in 4 or 5 big cities throughout the nation, demonstration projects of what I call rehabilitation power? A combination of one-stop services will be available: a] rehabilitation assists by the usual team for the cerebral palsied in the ghetto area, from infants to the aged - from medical through vocational services, but the aides and as many staff as possible would be drawn from job corps returning trainees in camps where they had been given instructions in working with cerebral palsied individuals, and b] place the cerebral palsied individuals with appropriate evaluations and some training and upgrade as many as possible to counselor and counselor aides - where in the same store front, there would be information given by the CP counselor, university trained - who is currently working on a down-graded level - or upgrade CP individuals from their current inappropriate workshop jobs and raise their level of expectation to a variety of jobs within the Store Front Clinic or Rehabilitation Facility in the middle of today and tomorrow's social and cultural upheaval problems.

The hard corps elements of ghetto-riot areas in the film were getting through to the deaf and communicating in the film as both sat at the mess hall tables. The speech of the cerebral palsied individuals has been greatly assisted by speech therapy - they can be understood - verbal encounter may have more of an impact and be a combined preventive measure and assistance in an area of manpower needs. Rehabilitation power can truly come of age in dealing with the socially and culturally deprived - greater handicaps - limiting features to the job corps returnees to confined community life than the physical limitations of the disabled.

### Third - Research Utilized Field Labs for the Cerebral Palsied

What of a suggestion for a demonstration in two or three places in the nation for the application of research and demonstration projects significant findings within a rehabilitation facility? After all, the generalizations of project #R & D 16 - on work evaluation of the cerebral palsied individual were generalized not only to other replicated projects, but to all other disability groups as worthwhile techniques to them as well.

Now, in reverse order, the significant findings of carefully selected R & D projects would be applied if possible in a laboratory facility with the cerebral palsied individual. The point would be to show that with a minimum of staff and apparatus, the techniques could also be used effectively to enhance the progress and achievement of the cerebral palsied! Here would be established research utilization - field laboratories, and, certainly, if the findings can be generalized to the multi-handicapped cerebral palsied, they can be utilized to perhaps a wider percentage of the severely disabled. For example, Forenta House in New York City for the emotionally disturbed is now also being used by the former psychotic deaf referrals from Rockland State Hospital in New York. Could, we, within this lab, test out the employer-site evaluation theory for the cerebral palsied? Could we test out techniques for leaderless groups counseling findings from our completed R D project at La Jolla, Calif., Western Behavioral Sciences Institute?

Monies are still available this fiscal year as we recoup funds from projects unable to utilize their money before June. The expanded division I now head includes the old VRA, R D program and 2 research branches from the old Welfare Administration with small dowries.

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# STATE LEGISLATION PROGRESS

Paul R. Ackerman
Assistant Executive Secretary
Council for Exceptional Children, National Education Association
Director - Study of State Legislation on Special Education, Washington, D.C.

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 22, 1968 Rice Hotel, Houston, Texas

In a panel entitled "Progress in State Legislation", it would be nice to be able to talk about state legislation as a process of progress. Unfortunately, it is not. Legislation, as the will of the people, may reflect a desire to change, but it is the implementation of this legislation that creates progress. Too often, when you expect me to talk about progress you expect me to delineate it in terms of quantity. That is not progress either.

I direct a study, which set out to investigate the process of state legislation and to analytically compare the legislation of various states. We succeeded in doing this, but, in ways unlike any you might expect and too complicated to discuss at this meeting. The point I am trying to make is that we found progress - but it was not necessarily progress in the way we thought it was going to be. Legislation itself was not progress. It only started it. It had to be implemented by imaginative leaders. It had to be funded in imaginative ways. It had to have supporting legislation. Too often legislation has been passed to meet the demands of interest groups or to follow trends and fads or to provide for political opportunism. This kind of legislative exercise has stimulated those involved but has failed to result in effective programs because it lacked the bases for effective administration.

In the dissemination conferences resulting from our study, we are committed to an analysis of state legislation as only one factor in special education change. In these conferences we will seek to train legislative planners who will see special education change its total ramifications - planners who will go beyond state legislation - planners who will match quality with quantity. With this framework, I want to review with you some of the latest landmarks and trends in state special education legislation. Remember that these trends and landmarks are only part of a total picture in any state's or, indeed, the nation's special education change. They are part of a picture which can only be complete if you think of complementing this legislation with appriations which are adequate, good relationships with the State Department which must administer the legislation and school systems receptive to the idea of program innovation.

1. The first landmark is a kind of state law which we have called "mandatory" planning. This kind of state law is that each school district shall design a long range plan to meet the educational needs of exceptional children and shall submit their plans to a state agency for review. This type of statute has generally been accompanied by laws mandating special education services at the end of this period. We have found, however, that to be effective, mandatory planning provisions must suggest penalties for failure to plan and must provide for increased appropriations. When mandatory planning has had these accompaniments we have found this kind of legislation effective in initiating improvement of special education service.

2. A second landmark has been state legislation which permits regional programs in special education. These laws have not only permitted but encouraged many school districts to join together to provide special education facilities for children with low incidence types of crippling conditions - children such as those with cerebral palsy. These statutes allow schools to pool together building resources for these children to a central location and have the financial base not only for special education, but for physical therapy, occupational therapy, special transportation, and other such needed services. When most effective, such legislation has generally been accompanied by statutes solving other multi-district problems such as joint ownership of property, interdistrict contracting, administration and the like.

3. The third landmark has been the establishment of regional instructional material centers. These centers, funded for the most part through federal funds, have been of service to multi-state regions by creating a centralized depository of special instructional materials for atypical children. A most important function of the IMC's has been to field-test equipment, curriculum, techniques and materials, train teachers in the use of new materials and media, make available not only to professional people in special education, i.e., teachers or administrators, but also to parents of atypical children who want to enrich their child's educational program. Instructional materials centers are increasingly being seen as state responsibilities. State legislators are moving (albeit slowly) to fund these IMC's on state or regional basis with state funds. As part of my project, I engineered the writing of model statutes toward state support of educational instructional material centers.

These three types of laws - mandatory planning, inter-district programming and state IMCs - we have considered to be landmarks in state legislation because of their power to radically change special education or give change proper support. However, we have noticed several other trends developing, which may have significant impact upon future programs.

We have seen increasing trend toward public school responsibility for preschool programs in all disability areas. For the past two or three years, it has become more and more "traditional" to furnish preschool programs for deaf children and blind children, but crippled children, mentally retarded children, and gifted children have generally been without such programs although they have demonstrated a need for them. Much state legislation has been changed to allow such preschool programming, but enforcement is still needed to make such programs an accepted responsibility of the local school systems.

Mandates for programs of special education are also increasing, as may be seen from the last report of the President's Committee on Mental Retardation. However, caution needs to be taken. Mandatory legislation is not a panacea to special education deficits. Many states with mandates are not meeting the charge of the law, while other states without such mandates are moving quickly toward meeting their obligations. Mandation is often only a legislative "gimmick" and can be used effectively only when other supporting statutes accompany it.

We are seeing more and more "architectural barriers" legislation, i.e., legislation which prohibits the building of school plants which are not adaptable to physically handicapped children, and less and less enforcement of these "barriers" provisions. One solution to this problem has been a compromise plan whereby a central school in a district is adapted for physically handicapped children.

Vocational Rehabilitation Service seems interested in assuming more education responsibilities, and we are finding contractural programs between secondary schools and VRA flourishing. So far there have been some conflicts in philosophy between the public school and the administration of VRA but it is predicted that, as these are resolved, cooperative programs will become more prolific.

Statutes defining exceptional children are beginning to take into consideration children with multihandicaps. Such children are most often children in which UCP is interested. As the term "multihandicap" becomes another category of special education, better provisions will be made for such children.

Transportation of exceptional children, particularly those with neurological and physical dysfunctions has long created problems of specialized equipment design and increased expense. State legislatures are beginning to consider the increased cost of transportation for exceptional children by enacting special funding provisions.

These are but a few of the current landmarks and trends in special education legislation. The federal government, as you will learn later, has become increasingly innovative in providing stimulation for new and special creative special education programs and, with some notable exceptions, the states have done likewise. Special education is in a period of intense and exciting growth. It may be in a position to assume, at a date 10 or 15 years hence, a total and complete educational program for all handicapped children. Until then, we will continue to witness increased changes in all approaches toward the rehabilitation of disabled children.

REMARKS BY

Walter H. Richter
Director, Southwest Region
Office of Economic Opportunity - Austin, Texas

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 22, 1968 Rice Hotel, Houston, Texas

Your program states that I have been assigned to round up a special state legislation for the handicapped. I shall, therefore, limit myself to certain topics which I believe are of interest to you.

In addition, I have been asked to tell you about the manner in which the Office of Economic Opportunity makes provision for disadvantaged persons, many of whom are, undoubtedly, handicapped or mentally retarded.

My first subject is: PKU

PKU is an inherited metabolic disorder due to the lack of an enzyme needed to break down phenylalanine, an amino acid found in proteins. When the enzyme is missing the partially metabolized products of phenylalanine build up in the blood. Brain damage and mental retardation result. When the defect is discovered early, the infant can be placed on a special diet low in phenylalanine and retardation prevented.

In recent years, various simple screening tests of the urine and blood have been developed for the identification of persons with PKU. Usually, newborn infants are subjected to a test before they are discharged from the hospital.

The blood test must not. however, be performed until the infant has been on milk feedings for 24 hours. A second test is usually recommended at 4 to 6 weeks of age to detect borderline or low levels of phenylalanine in the first few days of an infant's life. It will also confirm a positive initial test.

The frequency of PKU among newborn infants is reporter to be one every 8,000 to 20,000 births.

With the exception of six or seven states, each state, by law makes some provision for the testing of newborn infants for "PKU". In the majority of these states, the testing is made mandatory. However, in every state the law provides that the test is not required to be given or administered to a child whose parents object on the ground that it conflicts with their religious beliefs.

* * *

My second subject is: ELIMINATION OF THE ARCHITECTURAL BARRIERS. Under sponsorship of the President's Committee on Employment of the Handicapped and the National Society for Crippled Children and Adults, the

American Standards Association developed a set of standard specifications entitled, "Making Buildings and Facilities Accessible to and Usable by the Physically Handicapped."

There are thousands of public buildings in the United States that are not truly public. They are not open to all who might wish to enter. They are not open to the seriously handicapped. There are no barriers that say "Handicapped Keep Out." But they do have built-in barriers which prevent persons with physical disabilities from making full use of them, such as flights of steps to enter the building, rest rooms with facilities not suitable for wheelchairs and telephone booths too narrow for a wheelchair to enter or telephones with no amplifying device for the deaf, hazardous doorways, and so on.

If the handicapped cannot enter public buildings, they cannot hope to hold jobs there. Nor can they hope to conduct their affairs there.

Approximately 34 states have passed state laws to eliminate architectural barriers in public buildings and make them accessible and functional to the handicapped.

In April 1966, President Johnson announced the establishment of the National Commission on Architectural Barriers to Rehabilitation of the Handicapped . The Commission was authorized by Congress as part of the Vocational Rehabilitation Amendments of 1965.

The Commission will determine how and to what extent architectural barriers impede access to, or use of, facilities in buildings used by the handicapped. It will determine what is being done to eliminate such barriers from existing buildings and to prevent barriers being incorporated into buildings constructed in the future.

The general public -- you and you and you -- can let your wishes be known. You can tell responsible officials that you want these specifications to be made part of all public buildings. You can let them know you are in favor of any means and any programs which result in broader equality for the handicapped in your community.

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I would like to tell you about legislation enacted in the states on the subject of the BATTERED CHILD.

The Children's Bureau, charged with the responsibility since 1912 of investigating and reporting upon all matters pertaining to the welfare of children and child life among all classes of people, has in recent years, focused special attention on children who have been physically abused by other than accidental means by their own families. Physicians, social workers and others interested in the welfare of children are in a position to recognize many childhood injuries sustained through such physical abuse. Evidence of such abuse began to pour into the Children's Bureau.

In 1962, the Children's Bureau called together a group of consultants to consider what might be done. The members of the group agreed that these children were in need of protection by the community, but first they had to be found and identified before they could be protected from further harm. The group, therefore, recommended the passage of state laws which would require physicians to report these cases to community authorities as a first step in the protective process. As an outgrowth of the group's recommendation, The Children's Bureau, in 1963, published "The Abused Child - Principles and Suggested Language for Legislation on Reporting of the Physically Abused Child," to serve as guidelines for the states.

State legislations began to pass child abuse reporting laws during the 1963 legislative sessions, and by 1966, 51 such statutes were in existence, including the District of Columbia. Each state tailored legislation to meet its own circumstances. Therefore, there is considerable variation in the content of these laws.

Although the laws deal mainly with persons who are required to report cases of child abuse, there is nothing in these laws which preclude the voluntary reporting by persons with knowledge of physical abuse of children by other than accidental means.

The majority of the state statutes require the reporting of child abuse cases upon children under 16 years of age, others under 12, 15 or 18. California, Minnesota, Utah, and Wisconsin require the reporting of such injuries upon minors. Nebraska requires the reporting of any such injuries upon any child or any incompetent or disabled person.

Persons participating in the making of a report, who are usually physicians, institutions, nurses, social workers or law enforcement officers, who participate in a judicial proceeding resulting from such report, are immune from any civil or criminal liability that might otherwise be incurred or imposed. Some states provide such immunity if the report is made in good faith.

It is the intent that, as the result of such reports, protective social services shall be made available in an effort to prevent further abuses, safeguard and enhance the welfare of such children, and preserve the family life wherever possible.

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A very important subject in state legislation at the present time is: ABOLISHMENT OF CHARITABLE IMMUNITY.

A charitable institution, under common law, could escape liability in any action brought against it by interposing a defense that it was a charitable organization. This was based on the theory that trust funds created for charitable purposes could not be diverted for the purpose of paying damages arising from the torts of servants and agents. Another theory for such immunity from liability for torts was based, generally, either expressly, either inferentially, on public policy. A third ground of exemption was based on the theory that, where one accepts the benefits of a public charity, he exempts, by implied contract, the benefactors from liability for the negligence of the servants in administering the charity, at least where the benefactor has used due care in the selection of those servants.

In recent years, however, there is a trend throughout the country to abolish the charitable immunity defense of charitable organizations in tort actions, in some states by court decisions and in others through statutes. It is the law in some states that where a charitable organization has insurance coverage for negligence it is deemed to have waived its immunity from such liability for negilgence or any other tort.

It seems it would not be good public policy to relieve charitable organizations from liability for torts or negligence where innocent persons suffer through their fault and in the long run this will tend to benefit them and the public as well as persons injured. Further, it would be almost contradictory to hold that an institution organized to dispense charity shall be charitable and extend aid to others, but shall not compensate or aid those injured by it in carrying on its activities.

It is because of this trend toward abolishment of the defense of charitable immunity through court decisions and through statute law, that we have during the past several years, through our Bulletins and at meetings, advised our Affiliates to examine their liability policies to assure proper and sufficient coverage. In some instances, it may also be advisable to obtain malpractice coverage.

My next subject is: STATE LEGISLATION REGULATING SOLICITATION OF FUNDS FROM THE PUBLIC.

Numerous bills have been introduced in state legislatures on this subject in order to try to protect the public. A great many of these bills, if enacted into law, would have made it virtually impossible to conduct fund-raising campaigns because of severe limitation of the cost of solicitation. No voluntary health agency could possibly have kept within the cost limitation set forth in these bills.

Very fortunately, only a very few of these bills ever became law and the limitations of the cost of solicitation are being seriously considered in court proceedings. Of course, we all agree that, to the best of our ability, we should limit, as far as possible, the cost of soliciting funds from the public.

As a result of the introduction of all of these bills, the National Health Council appointed a committee consisting of the American Heart Association, the American Cancer Society, the National Tuberculosis Association, which is known now as the National Tuberculosis and Respiratory Disease Association, the National Foundation and the United Cerebral Palsy Associations. Mr. Harry Lyons, Director of the Legal and Legislative Department of United Cerebral Palsy Associations, represents our agency on this committee.

This committee unanimously agreed that there is a need for a device to inform and alert voluntary health organizations about proposed, pending and existing regulatory legislation.

This consultant group requested that the National Health Council urge all National voluntary health agencies to participate in this effort on a continuing basis. Since the majority of the regulatory legislative activities take place on the state and local levels, the success of this effort is dependent upon the complete cooperation of all affiliates of these national health agencies to keep the national office informed of such activities within their respective geographic areas.

This consultant group is fully aware of the fact that unless this regulatory legislation is kept within sensable and workable bounds, many health agencies might find themselves unable to carry on the purposes for which they were organized.

You may rest assured that United Cerebral Palsy will do everything possible to cooperate with the National Health Council to try to keep this so-called regulatory legislation under logical control.

Another subject I shall try to cover is: PUBLIC TRANSPORTATION OF THE HANDICAPPED.

Not many months ago, there was added to the President's Cabinet the Office of the Secretary of Transportation.

One of the important items being considered by the Office of the Secretary of Transportation is an analysis of the transportation needs of the handicapped.

Transportation provides access to the community and its activities. To the extent that it is unavailable to any group, that group is denied full participation in the society. The transportation system, as we know it today, either completely shuts out or unreasonably restricts one particular element in our society--those whose physical capacities are significantly below the fully-functioning individual. Transportation systems have been designed for those in the positive state of "good health."

There is a need to make our planning processes more sophisticated and/or humanly responsive in order to account for the broad range of physical capacities actually present in the population. There is also a need for a more vivid grasp of the transportation needs of the handicapped.

In the month of November 1967, the Department of Transportation in seeking an analysis of the transportation needs of the handicapped, invited many organizations to submit proposals to furnish research and study services under a contract with the Department of Transportation. The study is also directed toward aged people who are experiencing difficulty in using present types of public transportation.

It is apparent therefore that the federal government through its department of transportation, is earnestly seeking a remedy for the public transportation of the handicapped and the aged.

The material in the office at National indicates that over twenty million people may be helped under this program.

Panel Remarks of
Mrs. Margaret Kirkland
Director, Region VII, Division of Mental Retardation
Social and Rehabilitation Service
Dept. of Health, Education & Welfare
Arlington, Virginia

## RELATIONSHIP OF MENTAL RETARDATION PROGRAMS TO UCPA

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
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I bring you greetings from Dr. Jaslow -- as was mentioned, he is detained for legislative hearings. In asking me to pinch-hit for him, he gave me many of his ideas, so you needn't think that you are being entirely shortchanged by having a substitute.

I would like to talk more about the present more effective use of present resources, rather than to concentrate on ways to develop new resources. I think that too often we feel that the way to get better services for the people who need them is to get something new, and we would like to point out that much, much can be done in the way of better utilizing those resources which are already available.

I don't mean that it is not important to get new ones. There is a need for new and additional services which will continue ad infinitum. But I have just heard yesterday, on the radio, a statement about a study group in a county in Texas which has been charged to figure out how to deliver services more effectively, to the county, and they had discovered almost 300 agencies in one single county giving services to people.

And their primary recommendation was that some reorganization be developed whereby fewer agencies could give better service at lower overhead costs and to the betterment of all services. So I would like to address myself, partly, to this aspect.

In order to bring you up-to-date on the programs and services of the Mental Retardation Division of the Rehabilitation Service of the Social and Rehabilitation Service, I would like to - just for communication's sake - get into the federal alphabet soup.

As always happens, when you begin administering a program, you start out with a fairly clear notion of who it is you are going to serve, and then you find out that the grey area between those that you originally tried to serve and those who would like to be served - but you do not consider as eligible - suddenly becomes bigger than the black area that you knew you were going to serve. And so many questions come up, as to whether they have to be state operations, how big an institution, how old, and so forth, and, of course, new policy and regulation determinations have to be made as the program develops.

But it is still aimed primarily at the larger older institutions which need money to upgrade services. Primarily, throughout the country, institutions looked at their services and decided that the group of persons most frequently overlooked in terms of staffing, programming, even the facilities in which they are housed were the profoundly and severely retarded. And so many of the institutions have used their Mental Retardation project money to beef up the programs for these people. It was fortunate that some of the behavior shaping techniques and methods have been developed, just about the time the M.R. projects were developed and, consequently, these techniques have been applied across the country with spectacular results.

I always get amused by the way institutions measure success and on these dormitories for the severely retarded, one of the great expenses is laundry, and one of the most spectacular measures of success of these projects has been the rapid and drastic reduction in the amount of laundry being fixed for these dormitories.

This is no mean reduction in cost and also is very encouraging to those people who are working with the children.

Most of these projects are for the multiply handicapped. The inservice training projects -- various people have different words for this, but the inservice training program was intended by Congress to improve the knowledge and skills of the child caring staffs of these institutions -- the attendants, the house parents, whatever they are called.

The funds are also useful for the training of other parts of the staffs --the professional, the semiprofessional, the aides and so on--but the main thrust has been toward the training of the child caring staff.

It is a little more difficult to find dramatic results of these grants because the results are more diffuse and usually you cannot pinpoint, you cannot attribute to the inservice training program, the results that show up gradually; but no one has any doubt that they have greatly improved the services in the institutions. In many places, they have reduced a great deal, the turnover of attendant staff, and it has certainly improved the morale of many of the attendants.

An unusual project is being carried out by an inservice training project in this state. Most of the inservice training programs deal with how the staff of the institution deals with the residents of the institution. In this case, the inservice training director became concerned about the children and the families of the children on the waiting list.

They decided that if they would bring parents of many of these children into institutions on a one-day-a-week or one-day-every-two-weeks basis, they might be able to teach the parents how better to care for their children. And so they have. In these short-term, brief, intermittent training programs they have been able to teach many parents how to teach the child to feed himself; and in one case that they told me about, there was a father who wanted very much for his son to sit in his lap but the son was hyperactive and I don't know what the dynamics were, but he would not sit in his father's lap; and in one session of his training program, the son learned to sit in his father's lap -- and papa was satisfied. This was what he wanted. He didn't want to come back anymore.

But now, they finally convinced him that if they could teach him that quickly to sit in his father's lap, maybe they could teach him how to spoon feed himself, and this would please mama. So they came back and the child is now feeding himself and probably there are some other benefits too.

Now, this is a little unusual, but it is not outside the guidelines for the inservice training programs, and indicates some unusual ways in which these project grants can benefit the total institutional program.

The university accelerated program was provided to help meet the demand for highly trained and skilled professional help in the field of mental retardation and "other neurological handicapping conditions, sufficiently related to M.R. to warrant inclusion."

The unique thing about university affiliated program -- aside from the fact that it will make possible the training of many new professionals than are presently being trained -- the unique thing is that it will provide a different kind of training. It is not just a glorified typical training program in which whatever learning from other disciplines that occurs is purely incidental. For example, that the doctor and the social worker and the physical therapist get together over coffee and a certain amount of incidental fallout occurs, and the doctor learns something about social work and the social worker learns something about the other two disciplines. But in the university affiliated program, the interdisciplinary -- not multi-disciplinary -- but the interdisciplinary training of each discipline is built into the program. And further, one of the emphases is that the training program should not stop at the doors of the center, but rather that each discipline should learn what are the resources in the community that need to be involved in the services to the retarded, and what is the discipline's role in relation to those community resources.

For example, the pediatrician in training in the university affiliated center should learn that he has a definite responsibility to a day care program run by a welfare department or a private agency or whatever, out in the community, and even if there is a demonstration training day care center within the university affiliated center itself, the center cannot be all things to all of the clients who come through the front door.

The professionals within the center must involve themselves in all of the gamut of community programs as appropriate.

Another program is the community facility construction program that we fund and this is probably one of the projects in which you people who are most interested in community programs would be particularly interested. The purpose of this is to support the development of new and improved non-institutional services.

Related conditions may be included, depending on the degree of their relationship to retardation. For example, a child who functions as though he were retarded, because of his physical handicaps, might be served as long as the service were appropriate to his needs.

But we cannot find a building to serve, say a child who is bright, but because of behavior difficulties cannot fit in a public school because of an emotional problem. So we will have funds, which are administered through the State Construction Agency -- and the agency differs from one state to another, but it's the same -- and we work with the state agency on these community facility construction grants.

I always hesitate to mention the next program, because it has been such a disappointment to so many people because they have looked forward to it for so long. In the last M.R. amendments, a program was authorized but there has been no appropriation made to it -- and that is the initial staffing grants. When and if Congress appropriates money into this pot, we will be able to have a community staff in one of these newly constructed centers, or a new service, on a diminishing federal ratio basis, which starts off with 75% maximum for the first fifteen months, drops down to 60% maximum for the next year, then 45% for the next year and 30% for the next year; so that after 51 months, the community is expected to take over the entire operation of the Center.

The staffing money, if and when we get it, will help defray the expenses for all technical and professional services within the center.

Now, as to some ways that the United Cerebral Palsy Association and the Mental Retardation agencies, especially the federal programs, can work together -- it seems to me it would be to improve the use of the present resources and these are some of the ways that we suggest you might work with us and we might work with you:

For example, one of our greatest problems is terminology. To start off with, what is mental retardation? We have a definition, given us by the American Association on Mental Deficiency, which is the only generally used definition, but it is not satisfactory to A.A.M.D. and certainly not satisfactory to many other people. But nobody has come up with a better definition. Until we can define mental retardation, we certainly remain in a nice stew.

There are other problems. The overlap and confusion between the terms E.M.R. -- educable mentally retarded -- and the trainable mentally retarded, and then you don't get the last one because nobody likes to call you anything; versus the moderate, severe and profound continuum which -- and these two yardsticks don't quite match out -- you get a lot of confusion when people use these different terms and try to talk together.

In the field of services, we are getting all tangled up in terminology. What is day care? Is day care a baby sitting job en masse? Is it a public school requirement for all children or just for educable children or just for educable and trainable children, or does it apply to all children? Is it a medical program -- or is it all three?

I am beginning to wonder what a nursing home is. I hear about an eighteen or twenty-year old, mildly retarded, girl who has been through vocational training programs and can work -- they are working in the community, but they live in nursing homes. Is that a nursing home?

And the more we develop service programs within communities that take on a special flavor because of special needs and interests within a community, the more the terms get slid together. It is hard to know what it is you are talking about, when you use a term.

So we need to standardize our terminology and get it universally accepted.

We also need program standards. What is good day care? How much education? How much medicine needs to be involved in good day care? One of the great gaps that I see in the provision of day care in many communities is that often it is stuck into a community without any plan as to what happens when the child gets through with day care. And what happens -- they all say, where the clients are going to come from. They are going to come from the doctors and the schools and the families, and so forth, in the communities. No problem with that.

But then, we find a dead end over on this end as the children begin to grow up. They get so that they are no longer suited to the program that was established, but there is nowhere for them to go so they back up at the upper end here, and pretty soon the children cannot feed in from the other end because the space is all being used inappropriately, by adults who are no longer interested or suited to the program being offered. Now, in developing programs, it seems to me it is terribly important to include both the feed-in and the feed-out aspects of the program. What's the next step?

Again, I am using day care just as an example. These principles apply across the board. So often we develop a program and then put all children into it just because it's there. For example, you decide you are going to have one group in the day care center between the ages of four and eight, or you may decide that they are to be admitted to a group because of the physical size or it may be another age that determines your grouping, but then you commence to come across a child who really doesn't need a full day program with the group into which he fits because of what other criteria you have set up. We need to individualize the child and allow him to stay in one group according to his needs and they maybe join another group for a different activity. A doctor doesn't usually prescribe just penicillin -- he prescribes a certain quantity of penicillin, a certain strength, so many times a day, over a certain length of time.

In setting up program standards, I have too often heard -- and I am sure you have often heard people who say, "Don't rock the boat!" "Don't try to get better facilities! We had to work so long and so hard to get this basement facility and thank goodness we've got it, think of what it would do if we didn't have it; and, if you bug people too much about this, we are going to lose what we have!"

There is no point in penalizing today's children for yesterday's neglect and ignorance on the part of the general public. We must require adequate facilities for handicapped children, the same as for anyone else. But if you are timid and say "Don't rock the boat!", they will continue to suffer.

Another thing that we can work together on is to continue to help break down the separation of institutions from the community. Now, you have heard this many times, and there are many very realistic problems, but I would like to add perhaps some dimension to the older ideas, that it's not just a matter of bringing volunteers into the community and having staff from the institutions go out and talk to the community so the people know that this is not a jail -- that they do some interesting things and the kids are in pretty good shape. It is more than that.

The institution should be part of the community's system of services. Why should you have to duplicate in X town where there is an institution? Why should you have to duplicate in that town, the sort of services that are already built into the institutional program? Just because this happens to be a state facility?

The institution should be able to provide day care, for example, to residents who live close enough to it to make it more feasible for them to go there. Now, many institutions are going to shake their heads -- they are going to be all bothered by bringing in a bunch of people on a part-time basis, where they are used to the complete care and control of these people for twenty-four hours a day. But it can and is being done, and it must be done if we are going to make adequate use of the facilities we have.

It should also, of course, be a part of the regional service system, but in new and expanded ways, not just that they serve a region for residential programs, but for the training of parents -- such as the inservice training programs that I mentioned. It must be the center for many community located services, a training center, so that the staff of the center of the community services can come to the institution for training because this is certainly where most of the know-how is at present.

The institutions should use community services that are already available, particularly things like hospital services, rather than duplicating them on institutional grounds. The use of part time personnel, cooperatively, between community agencies and institutions. All of these ways of working together will help the manpower shortage which has already been mentioned as a major problem.

And another way to do that is to encourage and facilitate increased parent education and participation in the care and training of their children. If we are eternally going to look for somebody outside the home to provide the care and training of children, we are going to continue to be unable to meet the manpower demands; but there is no reason, as has been shown, in a number of local projects, why the parents cannot be taught to manage their own children quite effectively. Parents are often just as bright as institutional or community service personnel.

Now, the role of the UCPA in leading communities to move toward the continuum of care, a couple of suggestions for this would be: I have copies of suggestions for a model of services for the retarded and the handicapped, written by Dr. Jaslow. If any of you are interested, I will be glad to let you take, say, one copy, and if you need others you can write to the Regional Office and we will be glad to send you additional copies.

This outlines a very practical way of bringing together those services which serve all children or all adults or all people, but which have not been serving the retarded adequately, bringing those services together with specialized agencies.

Then, we need to develop new and additional services which will also bring innovation, invention and demonstration and we will be glad to work with you within those programs which we administer. But, as you look for funding, technical support and other kinds of help in developing services, your case will be strengthened, no matter to whom you talk, if you can show in what ways you have improved on the use of the resources already at hand prior to your asking for something new.

Panel Remarks of

Dr. Alice Chenoweth
Chief, Program Services Branch, Division of Health Services
Children's Bureau, Social and Rehabilitation Service
Department of Health, Education and Welfare
Washington, D.C.

## RELATIONSHIP OF CHILDREN'S BUREAU PROGRAMS TO UCPA

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 CONFERENCE
March 23, 1968 Rice Hotel, Houtston, Texas

It is my regret that the emergency which did occur kept Dr. Spektor from attending, but it is my pleasure to be with you.

We hear many statements these days about such things as health being a big business. It was referred to, I think, by our first participant. We hear a great deal about partnership for health. Certainly, none of us can do the whole job. We don't have enough money. We certainly do not have enough people. The more we accept the concept of comprehensive services, the more we recognize that it is very necessary for us all to cooperate.

As I was thinking about this program, I began to think about what some of our common concerns were, that is, I was thinking mainly of you and the Children's Bureau, at this point. First of all, we are --- partly because of latest legislation, the Child Health Act of 1967 has reminded us of this -- we are both interested in the area identification of children and bringing them under appropriate therapy.

We know that in general the preschool child is apt to be one of those who is not as well serviced as perhaps somewhat later. We know that special education is very important.

Another concern that I think is a common concern with us is that all of us believe in the adequate diagnosis, evaluation of the child because, certainly, the child who has associated sensory, perceptual or other deficits may be in such great need of service for his motor deficits. In fact, these may be the things which will prevent his total rehabilitation or his vocational rehabilitation as he grows older.

A third concern is, of course, prevention. And this is what all of us would like to see. I noticed in one of your brochures, something about Rh and one of our project people has been talking to us about the new scientific advance in that area. And Dr. Diamond of Boston has written a commentary in the January issue of Pediatrics and he starts out by saying that rarely has it been our good fortune to have a disease recognized, its cause clearly determined, a treatment successfully developed and then its prevention found ---all in one generation. We have great hope for this new advance.

Children's Bureau has been interested, since its gounding, in the goal that every child will be born well and be healthy. That means, on the preventive side, that he should have a healthy mother who is under adequate medical care. You have just heard a discussion of the whole child and this has been one of our philosophies, also, that the child should not be divided. Children with handicaps should get the services that they need to develop to their highest potential. We also want to see more of the bridging of the gap between what is known, what has been researched and what is practiced -- not only what is practiced, but what is available to all people.

On the subject of prevention, I just went to our reading room to pick up some of our literature and among other things there was a copy of "Mothers-at-Risk", an Adelphi School of Social Work sponsored conference, cosponsored by the United Cerebral Palsy Association with a grant from the Children's Bureau.

I also picked up another copy of one of our Children's Bureau Publications, which was prepared by your very able and charming consultant in nursing. I also picked up some selected readings for parents and one of the publications here -- "Tomorrow is Today" -- is one of your publications and the person who gave me this said that it was one of the very popular -- the most popular -- on the parents' reading list. So I thought you might be interested in some of those.

Since 1935 -- since the first Social Security Act -- the Children's Bureau has had three grant-in-aid programs, and, possibly, you know them fairly well so I will only say a few things briefly about them. The Child Welfare program and the State Departments of Welfare: at the moment, the extension of the Day Care services may interest you particularly, but two health grant-in-aid programs, the Maternal and Child Health administered by state departments of health and the Crippled Children's program which possibly you are more familiar with.

If I had some advice for a voluntary agency, I would say that perhaps it would be very wise -- and maybe this is unnecessary for me to say because you may already know the state directors of programs -- you have one of them, a former director of a Crippled Children's program on your panel today -- it would seem to me that you not only need to know the strengths and what they are and even though you find a small common interest, try to work on that, together with, and many of these programs have advisory committees and they would be very glad to consider people on those advisory committees.

Like all other constituents of the Department of Health, Education and Welfare, the Children's Bureau has regional representatives. You have seen one of those regional representatives as the previous speaker. On the health side, we have a medical director who usually comes from the field of pediatrics -- although he might come from obstetrics -- and is a public health person. We have a pediatrician who is usually specially prepared in the field of handicapped children, we have a medical social worker, etc. We have some other disciplines in our central office and I mention this only to tell you, to give you an idea of our interests. Obstetricians, physical therapists, occupational therapists, speech and health consultants.

The Maternal and Child Health program has been by and large a preventive program. No two state programs are exactly alike, although they operate under the same law and under some of the same Children's Bureau regulations. In general, these services have included maternity services, and, as time has gone on, we see in our urban areas a determination that particularly the family clinics should be declared in the public interest and therefore there should be no means test. Our Child Health services and Dental services in nearly all of the states are through the use of the Maternal and Child Health money.

The immunization programs are usually contributed by the Maternal and Child Health. We are looking forward to the time when we can help with a rubella vaccine -- the administration of a rubella vaccine -- which possibly is not too far off.

The trend in these programs has been toward more medical care services. It probably started when some of the states developed their premature care programs in which centers for the care of low-weight babies were established. I think these have been the precursors of what we are now calling the intensive care unit for newborns, high-risk newborns.

And the mental retardation clinics were mentioned, the fact that, in the early days, well, we have had earmarked funds for mental retardation since 1956 in the M.C.H. program. The fact that there were many physically handicapped children seen in the clinics has already been mentioned.

The Crippled Children's program was a medical care program from the beginning. It varies in the states. For the first time, we have a definition of a crippled child, which the Congress gave us in the Child Health Act of 1967. Some of the interesting words in our original law, however, which interest me, is the fact that we were looking not only to helping the crippled child, but to help the potentially handicapped child.

We have had certain regulations, the Children's Bureau has in that program, making children and youths to age 21 eligible; and we have seen, interestingly enough, in our latest reporting year, a 20% increase in the older age group. The diagnosis is free in this program. We have a philosophy that one cannot determine whether or not the family can pay for service until the child is evaluated. We do not know how long the care will be until we know what the problem is; how -- if he has a hereditary problem -- it may be that further children will be affected.

Even before the advent of the Medicaid program, there were a variety of sources for payment of treatment in that program. And now, many of the states that have Medicaid programs have made contracts or arrangements so that the children who have some crippling handicap and who are eligible for Medicaid may be - their care may be arranged by the Crippled Children's program but paid for from those funds.

As the name implies, it started out as an orthopedic program. But, interestingly, when I looked back some years ago at our early history of the program, the children with cerebral palsy were in our earliest clinics. Also, hemophiliac children came in very early. I think we would not classify these children as orthopedic now.

In the last several years, since 1950, the number of children has doubled, even though in the medical care programs where costs are rising so rapidly it has been very hard for our program to keep up.

The second largest classification of children in that program are the neurologically impaired - the children with neurological or sensory deficits. The orthopedic comes first with a little over a quarter of those children having that kind of handicap, and, of course, it is in the second category that the children with cerebral palsy come. This group constitutes a little more than 20% of the group and, interestingly enough, congenital malformations come next with almost as many in that category.

But, if you take a single condition, the largest category of children cared for under the Crippled Children's program is cerebral palsy, with more than 36,000 children. Since 1950 that has been nearly a 90% increase. The second largest, I was interested to find out were the children with congenital hearts.

Let me say just one quick word about two of our exciting new programs. One is the project grants that we have for maternity and infant care. Interestingly enough, this law grew out of a recommendation of the President's Panel on Mental Retardation, in which it was pointed out that there was an association between poverty and the fact that women got little or no prenatal care, and that women who got little or no prenatal care had a higher than normal percentage of low birthweight babies, and there was more neurological damage in these lowbirthweight babies than in the full-sized ones and so on. So it was recommended that we try to prevent this occurring in these infants by giving good maternity care.

These projects are for the so-called "high-risk" mothers and the "high-risk" has been, I think, liberally interpreted. It includes social, as well as medical risks. We find that, in these programs, we are dealing with families that are multi-problem families and it takes a variety of skills to help these families. One of the biggest problems has been the problem of adolescent pregnancy. We do not like to confine it just to the unwed because some of the legal marriages are very unstable. I have one other point I would like to make, and that is, because it has already been mentioned this morning, that many of these projects have developed services, homemaker services.

Some have had to develop their own on the project -- where possible, they have developed these homemaker services or, rather, utilized the homemaker services that have been developed in the community.

Family planning is considered a part of comprehensive care. One reason we are especially interested in family planning is that with the new methods, they require medical supervision and giving medical supervision between pregnancies actually accomplishes something that we have wanted to do for some time. We know that even though a woman comes in very early in her pregnancy, she has already passed the most critical period of that pregnancy. We think that these projects have had some impact. We are seeing a reversal of a trend in infant mortality in our large cities. This infant mortality had been going up. I have some figures, but I don't have time to speak about them.

It seems reasonable, though, that these projects will be in this direction because a disproportionate number of high-risk women are in these low income families who are receiving care. One of the effects of these projects has been to upgrade the services, particularly in the public hospitals of our country.

The other type of project is much the same and we call it a Comprehensive Health Service Group for Children and Youth. It's made to care for children from birth to about 18 years -- we haven't really defined the upper limit, but it includes both preschool and school age, we would assume that it would take in that much. This law defines, as far as I know, it's the only law which defines, what "comprehensive" is. Under this, both kinds of projects are to be developed in areas where there are concentrations of low income families. Seventy-five per cent of the grant is federal, twenty-five per cent must be matching.

Under the new Child Health Act, the Children's Bureau was also given money for some dental grants. We are abeing asked to try to locate these grants within an area where there may be other kinds of grants and I was going to give you an example of how the Infant Care grants and the Children's and Youth grants have combined with the community action programs of O.E.O. to develop an integrated family centered multidisciplined kind of health and medical care.

What are the opportunities for a voluntary organization? It seems to me there are many and I will only briefly mention some. I think one thing is that the voluntary agency can move, perhaps more quickly at times than a federal or state agency, in developing methods, some new program -- in other words, in demonstration. But I would like to emphasize what the previous speaker mentioned, and that is -- we talk about "comprehensive", but none of us has ever achieved "comprehensive." There is always some way in which we could improve the program. I think we have many ways in which we could do some cooperative work in improving what is already started. I think this agency should be congratulated upon its use of volunteers and you will notice in our new legislation the volunteer is mentioned.

We have been thinking about the involvement of some so-called normal children in experiences with handicapped children. I have an example in my own office of some cruelty on the part of normal children in relation to handicapped children. This is really because the children do not understand. Another example which has come to my attention is that -- the fact that -- your organization, I think, Rehabilitation and the Crippled Children's agencies in the New England area are cooperating in the evaluation of treatment of cerebral palsied children. The time is too short, I won't go into that, but a final example that I have here is that the White House Conference on Children and Youth is also in the early planning stage and this is another opportunity for a voluntary agency to get in with your ideas and your help on this program.

Panel Remarks of

Leonard Lucito, Ed.D.
Director, Division of Training Programs
Bureau of Education for the Handicapped
Office of Education
Department of Health, Education & Welfare
Washington, D.C.

## RELATIONSHIPS OF U.S. OFFICE OF EDUCATION TO UCPA

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
March 23, 1968 Rice Hotel, Houston, Texas

During the thirties, forties and most of the fifties, the activities relevant to the handicapped of the U.S. Office of Education were devoted primarily to the collection of information and its dissemination through publications and there were very little, if any, grant funds available.

Since the beginning of 1959, the responsibility was added to provide training grants to institutions of higher education, and to state educational agencies, for the preparation of personnel in the area of the mentally retarded alone. In 1964, the training authority was broadened to include all areas of handicap and at that time the research program was designed.

About a year ago, authority was given to provide funds to states for improving the services of education to the handicapped. As different responsibilities were added within the Office of Education, and as reorganizations one after the other occurred, the handicapped programs were started throughout the Office and the Bureau was established in 1967, to consolidate all of these programs into one unit, to give some coordination to the programs and to provide some leadership for future development.

In the light of this kind of history, it is not surprising that the Bureau has three divisions; one for research, one for training, and one for services. Each division has a number of branches and the divisions are coordinated through the central office of the Associate Commissioner. Now, let me turn to what is the Bureau currently doing and planning with respect to the cerebral palsied child.

During the 1967-68 school year, the training division is providing grants for the preparation of about 800 persons to prepare for educating the physically handicapped. These scholarships, awarded to individuals directly by the universities or the state educational agencies - not by our office, we give the award to the agency and then they administer. There are about 38 universities that have training programs where educational personnel are being prepared and about 400 students are engaged in this during the school year.

Twenty-eight other states, in their plans to train people to work with the physically handicapped, have about 413 scholarships being provided now. It is interesting to look at the distribution acrosss the type of scholarships we give and also the levels at which the people are studying. The Post-Masters, which is predominantly used for doctoral studies -- there are only nine people now matriculating under our scholarship program in the area of the physically handicapped. At the Masters level there are 148; the senior year level 92. Summer sessions, 272 scholarships and the special study institutes 292.

We are trying to develop more training sessions at the Post-Masters level in order to provide a larger number of teacher training, I beg your pardon, trainers of teachers, trainers of researchers and other leadership personnel. We are in some pretty dire straits in terms of educational personnel. Unfortunately, we do not have the leadership that is trained and without these trained people, to train the workers out in the field, obviously the services are going to be poor and restricted.

A pressing effort, therefore, is to try and increase the number of training programs in the universities at the doctoral level. We are also assisting training institutions to provide stronger course offerings at the other levels, and to increase the opportunities in the areas of the cerebral palsied and other multihandicapped. These groups, as other speakers have indicated, are becoming a larger portion of the youngsters that fall into these categories.

We have heard a talk of the university affiliate - the program of social and rehabilitation services and part of the response to one of the panel members -- there is a breakthrough in terms of cooperation across agencies. We are jointly working in the Division of Mental Retardation on university affiliated programs, in an attempt to put a special educator -- so we can avoid some of these people coming out, such as pediatricians, psychologists, psychiatrists, being uninformed in terms of what a special education program is like.

And so we have broken most of our rules and are giving larger funding than we ordinarily would be in a program development grant, and tried to provide -- at least, within the next few weeks, I think we will have made determinations -- five of the university affiliated sites with enough money to hire a high level person in special education.

And one more point, in terms of division of training -- and, then I will go through the other divisions. One of the most exciting current activities that I have become involved with, as the Director of the Training Division, is the initiation of what we are calling our "special projects." This thing is about a month away, I hope -- we hope to get it through in about a month. It is pretty close to being initiated. It has become obvious to us that we needed some new mechanisms to continually improve the regular part of our training grant award program. We needed to develop new models of training which would take into account the new concepts of education, the push in educational technology and media, plus the possibility of training new groups of professionals and other supportive personnel in order to meet the manpower needs.

So, the general notion was we have a major, regular part of our program -- let's take some risk money and try to develop some new models, some new prototypes, we will (if this thing goes through) (and I am pretty sure that it will) provide planning money to write a proposal. The kinds of issues that we are talking about are so complex that a professor at a university or some professional in another agency just cannot take it out of his hide and work at night and come up with the kind of proposal that we are looking for, so we are willing to support someone to write the proposal. Furthermore, if at the end of the grant period, say, in a year, the idea is still good and it looks like it's still viable, and the proposal is not adequate, we are willing to continue on the planning end of it. Then, of course, we would like to see the plan put into action, initiate it and implement it.

After the plan is in, we would then cut in one of the other divisions of the Bureau, the Research Division, for an independent evaluation to see if this concept and the program that grew out of it really is a viable one that should be put into the regular part of our program. So, this is the most exciting part of our program and training -- as I see it at this point.

Now, turning to the Research Division -- the Research Division is, like most research divisions in the federal government, it has wide broad authorities to work with all types of handicapped and it has begun a number of activities related to cerebral palsy. It is a new unit -- it really began to be implemented in 1964, so we do not have many projects completed; but I know one that has been concluded to date and it is a project to modify teaching machines for use in teaching severely involved children.

Other studies are under way, that deal with neurological impairment various aspects of this and perceptual disorders and things of this kind, all of which we feel will be having some sort of application for the cerebral palsied.

In addition to the individual projects, the Research Division has been supporting fourteen regional instructional materials centers and these were supported on the basis of the demonstration. They are large, multi-functional operations which include a number of things. They are to collect instructional materials for all types of handicapped children. They are to disseminate information about these materials and train teachers and other professionals in the appropriate use of these materials. They are to evaluate the materials that are on the market and that are homemade by teachers and disseminate the findings of such evaluation, and they are also to enhance the improvement of the existing materials and the development of new materials. None of the centers is fully operational.

Most of them have been in operation only about two years. The project was conceived of as a six year project. The first three or four years in getting functional, the last couple of years to demonstrate its worth. However, there are some centers around now and like most of them, are beginning to give some service to the teachers and other professionals.

There is one close by -- the University of Texas has one. And if you are from this neighborhood, I would suggest you go down and look at it, it would be a very interesting experience. Presumably, once these are really operational there will be a retrieval system with the use of computers, so that professionals wanting material will be able to request information and get it back in a relatively short period of time.

And then there will be consultant services from these centers, and some satellites that are being identified and developed along with them, so that actual appropriate use of materials can be gained through workshops, consultation and other kinds of mechanism.

Let me give you a few instances of the kinds of the services that are rendered in the Division of Services. This unit is the newest type of program in the Office of Education for the Handicapped. And it administers funds to assist states to improve educational services of the handicapped. They are currently -- I was able to identify about 52 state supported schools throughout the nation -- providing services to cerebral palsied children, and they are receiving the funds from the Title I of the Elementary and Secondary Education Act.

Another Act which was a Title II of the Elementary and Secondary Education Act - there are funds now being used for integrated projects at the local school levels. The past session of the Congress stipulated that 15% of these funds should be used with the handicapped. I heard an estimate I don't know how accurate it is, but some of the states are using around 9% so there should be additional funds so that the local school units might be able to develop.

The general legislation with the last amount of money -- by the way, some of these other programs I am talking about, thirty million dollars and twenty-four and a half million -- but the real general, broad gauge legislation that supports the service division has fourteen and a half million in it. It was authorized for one hundred fifty and we got fourteen and a half. We hope we can jump it up to thirty-two and I am going to go back for some hearings in a couple of weeks. At any rate, this is a broad gauge of support to state educational agencies to improve the program, the educational programs for the handicapped.

Now, in the past session, we got an awful lot of new authorities and I will mention a few that I think might be relevant to this group. We don't have any funds for them yet.

One of the new authorities was theestablishment of Regional Resource Centers. The notion was to set up some model excellent centers where we would want to bring together the diagnosis and then actually do the follow-through with the educational treatment of the youngsters. And, in education, we have been very neglectful and very hard put because we have diagnosed the heck out of those kids and then we don't follow through. This is an attempt to pull them together in one place and to set up model programs which then, we hope, we can disseminate out to other educational groups.

The multiple handicap you have heard of over and over today, and we have the authority now to set up some blind centers. This was stimulated by the rubella epidemic. I think we are talking now about a different kind of youngster, coming out of the rubella epidemic, than the usual deaf-blind traditional notion.

There has also been an expansion of the caption film for the deaf. Now, it is broadened in two senses - one, we are no longer talking about films, caption films; we are talking about media in general -- the new technology; and, second, it is no longer restricted to the deaf, it includes now all types of handicaps.

Another authority was to train and to do research in the area of physical education and recreation for the mentally retarded and the handicapped.

And the last point I would make, which is, that we have now the authority to provide information and recruitment in the area of the handicapped.

Now, that term "information" I think is a little misleading; because what we have in mind at this point, and let me mention that we have committees right now working to try and set up the guidelines and regulations to conceptualize this out of the framework of the law. I think most people when they think of information, it is a matter of broadcasting and mass media and publications. To repeat, this "information" part of the law was not of this type, although it is possible to do it under that.

The primary intent was to work with parents, so that they get the information -- they can get the services that their children need.

Now, the kind of thinking that is going on now -- and I can speak a little more familiarly on this because I happen to be the chairman of this committee -- we are thinking about really broadening the notion of information giving. We are thinking about trying to set up some prototype centers -- one in an inner city arrangement, on in a sparsely populated set-up, another in the suburban set-up -- in which the family would -- it would not be taking in the handicapped child, it would be taking in the family. And there would be someone to work with the family with skills in parent counseling, who knows the social agencies, who would get the parents, if necessary, the appointments; get a baby sitter, if necessary, for the siblings. In other words, follow the case through until the parent has had some satisfaction and until all the resources are completely exhausted.

There is an interesting wrinkle on this. We think that if this is done, and the resources are exhausted, either in terms of the type of resource now being available or the quantity that is now available, we think part of this information giving ought to be to the power structure within the community, in order to make decisions about increasing the resources. So we are broadening the concept of information giving, not only to include the parent and the child, but also the family constellation and now, also, the community; giving it the kind of information so it can make wise decisions.

I think we have heard several things coming out. I think we are hearing a blurring of lines, both in the categories of children and we will start talking now about how we serve this child, and the specialist who is in, say the visually limited area or the deaf or speech. They are beginning to talk more and more to each other and to realize that each has a body of knowledge and they are not as afraid to deal with one who doesn't belong in their category. This is a blurring of lines coming about in terms of categories.

Then, I think, there is a blurring of lines also occurring across agencies. I indicated we are beginning to work with S.R.S. The philosophy and policy that our Commissioner is pushing is one that tomorrow S.R.S., and the next day maybe we ought to get out of H.E.W. and find somebody we can work with. And who knows where we go from there.

If you cannot solve the problem with one group, maybe we can start giving some joint funding. I think this is on the horizon. I think you people can help us by not trying to ask the questions that will fit our administrative structure. Give us problems that is what I am saying to you. Talk about issues that have to be solved out there in the community; not in terms of our structure as we have it there in Washington, but let us try to find the resources within the government to try and solve the problem.

This, I think, would be a big help to us. Because if you give us the questions right in our neat little categories, we will solve them that way for you. By the way, I don't underestimate the difficulty of doing this. It is a big machine up there and I have been impressed in the few months I have been up there. It is hard to move. But it is moving. So, bear with us a little bit. I am sure the general tenor, as I see people up there now, is becoming one of trying to cooperate with one another.

I have some specific points -- but let me make one more major point - and that is - as a new group - organized group in the government, we would like to use your machinery. We have problems of recruiting people into the field; you are out in the field. The best recruiting I know of in getting young people interested in coming into special education is, for them to work with handicapped kids. I have heard all kinds of schemes to get these youngsters invited, the career days and all this, but the real payoff, when you look at who comes in, is the youngster who has had camp experience, who has worked as a volunteer in an institution. You people know volunteer work. Help us, is what I am saying. Let us use your machinery.

Also, in terms of using your machinery, you people have cut across many disciplines for many years and you know how to do this. Education has not been that forward and we could use your help in this kind of thing. You can put us in the kind of context and help us to reach the kind of people we ought to be reaching and everybody is talking about it now, and we want to go forward and start to implement some of it.

# COMPREHENSIVE HEALTH PLANNING

W. L. Olsen
Regional Director, Region VII
Comprehensive Health Planning Program
Dallas, Texas

Presented at UNITED CEREBRAL PALSY ASSOCIATIONS' 1968 ANNUAL CONFERENCE
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The Partnership for Health concept and the Comprehensive Health Planning concept is somewhat of an amoeba. It is poorly defined, purposely not defined by the federal government, because intrinsic in the Partnership for Health Act, Public Law 89749, is the fact that the legislation intends to put the burden of planning upon the state or local communities. But, if I may use the analogy further, in all sincerity, if it is an amoeba, a one-celled animal, if I recall my zoology, if the cell is the planning agency, I would sincerely emphasize that in my opinion, it is people such as you who are the protoplasm life matter of the entity.

Now, let me attempt to focus on something that I would call a myriad of health problems. But not just problems -- casual factors.

I think it almost axiomatic that we are very much capable of defining problems. We are capable to a lesser extent to define casual factors. But it is the casual factors, however, that are critical -- because we do not attack symptoms with lasting success; we attack causes.

Section 314a of P.L. 89749 is a grant of money that Congress awards to a single state agency, based on a formula and usually involving population and per capita. Under Section A, the governor is asked to designate a single state agency for Comprehensive Health Planning. He may elect not to designate such an agency. Accordingly, the whole thing at the state level could just die aborning. I have some figures on the batting average so far on the states and territories. Most of them have designated such agencies. Out of this 314a grant, for example, the state of Texas will get $250,000 a year; a state Health Caring Director will be hired; a planning staff, and health advisory council - made up of a majority of consumers - will be established to set up, to provide a mental sounding board, ratify recommendations of the staff and what have you.

This advisory council is a balance between the consumers and the providers. It is a balance between official agencies and voluntary agencies. But keep one thing in mind, the governor is the one that takes the initiative in designating a planning agency. He can place it almost anywhere he wants to and it is only through the process of (Heaven forbid the term) plan for planning; i.e., a state program for planning, that we can determine, at the federal level, what the makeup of this advisory council is. Through this review process, however, we are holding the states, of course, to this balance between consumers and providers.

Now, the charge of this agency is quite abstract. The charge is to develop a comprehensive plan for health services and manpower facilities development. Call it a blue-print, if you will. It is a plan in which we feel you will never have an end. It is not a 1940-type planning approach, where we come up with a set of recommendations that are beautifully bound--and thrown on a shelf. The plan is geared to action and operation. Again, I will get into some concepts of this.

314b of P.L. 89749 is for the State Health Planning Agency -- for the "CAHP", Comprehensive Areawide Health Planning Agency. This can go to a non-profit organization. It can go virtually to any legal organization except the State Planning Agency or an extension thereof.

This is charged, in a sense, by the legislative intent with the same process to be conducted at the state level; namely, to develop a blueprint for long range and immediate development, coordination, utilization, in areas of health, manpower services and facilities. This, too, must have as part of the professional core of planning agency, an advisory group made up of providers and consumers. As an aside, the consumer, I think, is being more or less defined. We are talking about not only the traditionally influential consumer, but the previously unheard - and I would add that it is the problem of the community to decide how to get an effective previously unheard consumer, how to get a man from the ghetto, a man from the lower income, traditionally, inarticulate group, to contribute in a positive manner to this process.

314c of P.L. 89749, I will skip over quite lightly. Congress elected to provide funds for curriculum development and academic centers to develop health planners.

314d of P.L. 89749 is another form of the grant; but, here, we get into the service grant area. One time-consuming discussion is the evolution from categorical formula grants to each state into a single block grant. This is what we have. The only vestige of category is the fact that of the four million dollars -- a little backed up -- of the approximately 4.5 million dollars annually awarded to the state of Texas, 15% -- at least 15% -- must go for mental health. This is not truly a vestige of categorical interest, but think the pragmatic recognition that about 40 of our states have separate mental health agencies and you would have a real crazy quilt of administration if you took the mental health department and had it transferred out. But that 15% was a minimum figure, if there is a logical reason for it, this figure can be changed -- 25%, 75%, whatever might be the need.

These funds, which used to come to the state in nine categories now come in this one category, and are available to voluntary health agencies, read the fine print. This is not generally known, not generally publicized, but each state health and mental health authority must provide -- again, the annual state plan that the public health service reviews and approves before they get the money -- must provide procedures for reviewing applications from other agencies and give us their criteria for deciding whether or not a project is worthy of funding. And their criteria for how much they would ask a voluntary agency, for example, to share in the cost.

Interesting thought: an interesting offset for the fact that the individual categories have disappeared. I am sure that this issue of going to a block grant -- in both these two service areas -- I am sure this loss of categorization has been quite a concern to many of you. But I have given you one offsetting factor, i.e., the state health and mental health authority must provide for contracts or redraft of little agencies and then, secondly, the whole planning process itself should need -- should lead to an appropriate assessment of needs of health problems and this will have an influence on the program . . . .

Now, I contend that you can get at this whole amoeba called Comprehensive Health Planning by starting with some building blocks, modules, if you will. Consumer has a need, a health need or a problem of some kind. This provider has a skill. Now, these two get together through the service connector in a real simple module, such as take in health care . . . . .

And what is the big question right now? The big question in the minds of the provider is what effect will this super agency have on my own operational planning. And this is a valid question that needs to be raised in every state in this union. Because there has got to be a clear understanding, and each state has to work this out, as to the distinction between total planning as it is conceived by the Partnership for Health Act, and specific operational planning. . .

Regarding the charter to the State Health Planning Agency. One of the objectives is to provide for encouraging cooperative efforts among governmental and nongovernmental agencies, organizations and groups concerned about services, facilities or manpower, and for cooperative efforts between such agencies, organizations and groups in the fields of education, manpower, rehabilitation. You are in this ball game.

A working definition of Comprehensive Health Planning is viewed as a process of national decision making about the use of public and private resources to meet health needs. . . . .

So now, moving into recommendations. Communications, as a first step of action. If you do not know whether your state has a State Health Planning Agency, find out. If you find out that there is a state health planning agency, find out if there is a health advisory council. Find out how you are going to get on that council. The size of these councils range from about twenty-five to eighty; and consider why. If you pick up a phone book in a metropolitan city, the size of New York, or Houston and look in the yellow pages for voluntary health agencies, or however they are characterized, you may find as many as 25 or 30 chapters. Now think of what it is like in the state capital.

Voluntary agencies may have to consider another device, that is, getting together and expressing a willingness to the Governor to send a couple of delegates, representing the idea of voluntary health agencies -- because I think some Governors are going to shy away from voluntary health representatives of individual agencies, thinking that they have a vested interest. This is a prejudice that you are going to have to overcome. Show your interest or willingness in the total concept of sorting out these health problems, needs and resources. . .

There is even some gray area between that which would fall under Social and Rehabilitation Service, and that which would go to Public Health Legislation. But don't worry about it. Get your ideas down, and we will exchange them. Many, many projects -- I am interested in this concept of a two or three page synopsis of an idea -- get people thinking about it!

# REPORT OF THE MEDICAL DEPARTMENT TO THE BOARD OF DIRECTORS UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

March 21, 1968
Houston, Texas

**STAFF:**

Brewster S. Miller, M.D., Medical Director
Isabel P. Robinault, Ph.D., Coordinator of Professional Activities
Sherwood A. Messner, Director, Services Section
Una Haynes, R.N., Associate Director, Services Section, and Nurse Consultant
Ernest Weinrich, ACSW, Assistant Director, Services Section
Carolyn Levine, Social Work Interne from New York University

I have the honor to present to the Directors the "State of Cerebral Palsy" report for 1967-68 from your National Medical Department.

## I. Introduction:

You may recall that I attempt to introduce these Annual Reports by drawing on the wisdom of our forebears. In 1881, John Morley, writing in the Life of Richard Cobden, pointed out that, at that time, "great economic and social forces were flowing with a tidal sweep over communities that were only half conscious of that which was befalling them. Wise statesmen are those who thus foresee what time is thus bringing, and endeavor to shape institutions and to mold men's thoughts and purpose in accordance with the change that is silently surrounding them." While I am uncertain how silent such changes are today, certainly we are in the midst of a whirlwind of social and economic and cultural change, which, if we are perceptive and skillful enough, can be used to the advantage of the children and adults whom this agency is dedicated to serve. So, all of us, in this cause, have a responsibility - a personal responsibility - to see to it that we use the very best that we have within us if each is to make his special contribution to our objectives.

No one has put it better than John Gardner when he said, just before his tragic retirement last month, "No factor has been more conducive in the emergence of big government than the failure of the private sector to look squarely at the real problems of the community and the nation. Today, each of the varied segments of the private sector appraises its own special problems but none examines the larger issues facing the nation. As a result, these problems end up in the lap of government. If we are to retain any command at all over our own future, the ablest people we have in every field must give thought to the largest problems of the future. They don't have to be in government to do so. But they have to come out of the trenches of their own specialty and look at the whole battlefield."
The costs of delivering medical and related professional care to handicapped and ill Americans remains a Herculean challenge to both public and private agencies, and coupled with the National Institutes of Health projection of over 436,000 children with cerebral palsy in 1970 -- you will recall that there are at least 20,000 brain damaged children as a result of the German measles epidemic in 1964-65 --pinpoints our challenge and responsibility.

Fortunately, considerable light is shining at the end of the service tunnel which beams directly on our goal of providing or supporting a myriad of services to cerebral palsied children and adults. Mental retardation legislation and consequent programming has broadened its charge to include the physically handicapped. The returns of the states' planning programs in vocational rehabilitation are now in and new state activities in evaluation, guidance, training and work activity and sheltered workshop programming are commencing.

I like to think that we, in United Cerebral Palsy, are examining John Gardner's larger issue of our future in this cause and are taking leadership steps to mold them for the good of those we serve. We shall hear tomorrow of the implications of the "Partnership for Health" legislation ---- the Comprehensive Health Services Planning Program -- and the Regional Medical Programs for our charges with cerebral palsy. While the latter program will have its initial impetus on patients -- his care and rehabilitation -- overlap and are directly related to much of our service programs for cerebral palsied patients. I feel confident that our Affiliates can qualify for assistance from this source.

## II. Regional Service Program Hearings:

Well, then, with such tremendous Federal and state efforts, what is our role in the private sector? The past several months have shown a degree of cooperation and constructive activity in the service and special education areas never before accomplished between Affiliates and the National office. I refer, of course, to the Regional Service Program Hearings. We have completed five, and the sixth for Federal government agencies and sister voluntary health agencies will end the cycle tomorrow. My staff and I have been greatly impressed with your homework -- with the careful analysis of our preliminary plan by Affiliate Boards of Directors, Professional Advisory Committees, and staff and the very large number of recommendations, constructive suggestions and endorsements. In planning for our program for the next five years, it is vital that the planning be a joint effort between Affiliates and National. Far too often we tend to overlook the fact that this is the United Cerebral Palsy Associations -- neither Affiliate nor National can do the total job singly, but together progress is made and each day we come closer to our objective of putting ourselves out of business.

It would be unfair, of course, to prejudge or even to predict the recommendations of the convocation, which is to thoroughly study the entire mass of data and recommendations next month, to the Operating Board of Officers in June and the Executive Committee in September. But, several themes run through each Hearing. Affiliates are looking for guidance, for planning concepts and assistance from the National staff. Most Affiliates testifying expressed the need to continually upgrade the experience of the staff across the board -- the need for aggressive and forward thinking inservice training programs, development of effective service programming for the teen age and young adult were continually emphasized as specific new directions in which UCP should go in the next five years. Your staff is not awaiting the final determination of policy in this matter, but is scheduling a planning conference to develop specific program concepts and methods for the cerebral palsied adult who cannot work in either competitive or sheltered settings in New York next month with representatives of the National Association for Retarded Children, the Easter Seal Society, the Kennedy Foundation and two branches of the Social and Rehabilitation Service.

## III. Relationships with Mental Retardation Programming:

Much of this stemmed from a most productive meeting held with the Subcommittee on the state of the problem of the President's Committee on Mental Retardation in October, where UCP was represented by Mr. Goldenson, Mr. Turnheim and several key staff people. We presented ten specific areas where we felt that UCP and that Committee could work closely together and which have important implications in both fields:

1. Day time activity programs for severely multihandicapped children and adults;
2. Information, referral and follow-along services;
3. Service program aspects of architecture;
4. Improvement of care in state institutions;
5. Alternatives for institutional care;
6. Protective services for the handicapped;
7. More accurate determination of case load and survival;
8. Inclusion of cerebral palsied patients into programs for the mentally retarded.
9. Standards to evaluate total services;
10. UCP representation on advisory committees to national bodies, including Federal agencies.

We are honored that Dr. Kugel, Chairman of the Subcommittee, will discuss one such need for us tomorrow. Mrs. Haynes was invited to share our concerns for care of the severely multihandicapped patient in state institutions before the Committee on a particularly snowy day in Boston. She made an especially useful contribution to this program and, on your behalf, I want to publicly express our appreciation to her.

Dr. Helsel, Mr. Cunerd and I represented UCP at a meeting of the Secretary's Committee on Mental Retardation in February and have developed a working relationship with that group within the office of the Secretary. Representatives of six key Federal agencies will tell us tomorrow of their plans for programs involving cerebral palsied individuals, and to make recommendations to us as to specific areas wherein we can and should be working closely together for better services and to suggest to us areas of pilot or demonstration programming in which UCP can take the lead in pointing our specific needs and how they may be met. Let me emphasize the need to understand clearly the tremendous potential for the "Partnership in Health" legislation being translated into comprehensive health planning for health maintenance, prevention, diagnosis, treatment and rehabilitation and for facilities and personnel, therefore, this provision for such comprehensive health services is beyond the responsibility of any one group and its achievement for all our citizens, particularly those disadvantaged ones, depends on a partnership between government and voluntary efforts.

## IV. Joint Planning for Community Services:

We are especially gratified that key individuals from our sister agencies will be testifying at a Hearing tomorrow afternoon along similar lines - Mrs. Elkin, President of the National Association for Retarded Children, Mr. Whittier, Executive Director of the National Society for Crippled Children and Adults, Mr. Massey, Vice President of the National Foundation and Dr. Kugel, Vice President of the American Association for Mental Deficiency. I feel it essential that we actively work together if we are to form a united front against threats - groups such as the United Health Foundation and others who want to treat "the whole man" without real knowledge of the need for specialized attacks on specific health and educational problems.

More and more Affiliates are discovering two and two make five, in terms of rendering and extending services in cooperation with other community agencies. With such far reaching social and economic change, we can no longer afford the luxury of isolation in our program but must actively participate -- and also take the necessary leadership in cerebral palsy - with sister groups if the job is to get done within the financial limitations of each. To this end, your National Medical Department this past year called a planning conference of Executive Directors of state and local Affiliates wherein such activities have been successful to structure a series of regional workshops to assist all echelons of UCP in planning. We see three specific objectives for this program:

1. To make Affiliates aware of the need to carefully plan their total program to deliver the maximum of services most effectively for the dollar we spend.

2. To emphasize the need for program planning on a continuing basis, year in and year out.

3. To portray the structure and methods by which such community service program planning takes place, including the meaning of community organization and the complimentary roles of volunteers and staff, both internally and externally.

In this series of regional workshops we see the need to meet several problems head on, such as the natural resistance to turn over support of existing services to public fund sources and move into new pioneering ventures and having the flexibility to make such moves; lack of initiative in making application to public sources for support of existing services and carefully planning the means of continued support when seed or demonstration money runs out; the knowledge of how to evaluate ways by which UCP can be most effective in serving cerebral palsied children and adults, etc. We agree that education and medical care are the basic right of every citizen. It is the right, duty and responsibility of public funds to provide them. By our assumption of such services on a long term basis -- not demonstration or pilot programming --how often do we actually prevent public sources from taking on their responsibility? We can, and should, make it possible for the community to serve handicapped people and take the lead in pointing the way for others to participate in and support service programming.

With the development of our five year plan and active participation by all Affiliates in these regional conferences on planning, we should be well along toward innovative and creative uses of our income at our twentieth anniversary next year.

In this regard, I would like to mention two programs quickly. More and more parent groups are forming to develop services for their brain injured children or children with minimal cerebral dysfunction. To prevent the proliferation of still more agencies, particularly on a national scale, and to assist in seeing to it that education, psychological, and work activity services, which parallel the needs of our cerebral palsied children are provided these children, can we not extend the right hand of partnership with these groups and bring their strengths and weaknesses into the UCP fold for the betterment of each child whom we are each dedicated to serve?

In addition to our real need to detect brain dysfunction at an earlier age, where do we stand in accurately predicting the pragmatic future of cerebral palsied children early in life? I believe we must continue to emphasize the need to start vocational and social evaluation of children, instead of 17-18 years, at ages 11-12, where appropriate occupational and social education can begin. Earlier preparation of children will have important program ramifications in the next decade.

We have commenced to make concrete efforts to coordinate our efforts with the National Foundation. whose birth defects program does not compete with our own, but wherein many common factors are present. Stimulated by discussion at the Foundation Directors meeting in June, Messrs. Goldenson, Hausman and Firestone, together with your Executive and Medical Directors, visited Mr. O'Connor and Mr. Nee in December. As a result of that initial conference, Dr. Apgar, the Foundation's Director of Research, and I have met to develop a method of better coordination of our efforts in scientific research. This development augurs well for the hoped-for cooperation in other areas as well.

You will recall that, in my report to the Executive Committee last December, I emphasized four areas of concern that we, as a staff, see time and again in National's cooperative evaluations of Affiliate service programs. They bear repetition now, for I sincerely hope they will be subjects for discussions in depth by your Professional Advisory Committees as they counsel and guide Affiliate Boards of Directors in their responsibilities for serving handicapped people within your communities:

1. Continuing need for earlier identification and referral of infants and very young children to programs having prophylactic focus.

2. Paucity of services for the multiply and severely involved individual with cerebral palsy; and lack of involvement by our Affiliates with programs in state institutions for the retarded.

3. Need for sophisticated and comprehensive evaluations that are geared to providing concrete data on the motor, sensory and intellectual deficits and recommendations for teaching or training around these deficits.

4. Increasing evidence that much of the impact of service is lost unless a continuing relationship or partnership is developed between the family and some agency providing an information, referral and follow-along service -- preferrably a UCP Affiliate.

## V. Staff Activity:

Since the time of the last Annual Conference, the Services Section staff has continued to spend a major portion of its time in doing evaluation studies for state and local Affiliates. This included four state-wide studies [Washington with visits to 18 counties; Missouri with visits to 46 counties; Maryland with visits to 10 counties; and Illinois with Visits to 31 counties); plus ten studies for individual community Affiliates in eight different states. Some of these visits were made by consultants functioning as members of a study team.

In addition, on-the-site consultations were provided by the staff for nine local Affiliates; and on six occasions, staff members addressed annual meetings of state and local Affiliates. Seminars for professional personnel of other agencies, mainly nurses, were conducted in thirteen different Affiliate areas. At least four of these included public health nurses from the State Departments of Health and one was for all army nursing personnel in the Washington, D.C. area. There has been participation in university courses in five different states and eleven inservice training programs were conducted for personnel of state institutions for retarded in nine different areas.

The staff also represented UCPA in meetings of various national level agencies or organizations, in many instances making formal presentations or participating in panel discussions. These included the American Association on Mental Deficiency, the National Conference on Social Welfare, the National League for Nursing, the President's Committee on Mental Retardation, the American Academy for Cerebral Palsy, the New York State Rehabilitation Association and a special conference on minimal brain dysfunction conducted by Pathway Schools.

A major portion of staff time and energies was devoted to planning for, organization and attendance of the Regional Hearings on the Five Year Program Plan. In the five regional hearings, presentations have been made by representatives of 65 state and local Affiliates. In addition, several regional vice presidents and members of professional advisory boards have made formal presentations. Serving as members of the panels have been seven National officers, six regional vice presidents or state presidents, thirty members of the professional advisory committees and six local, state or regional staff representatives.

It may be reassuring to know that each member of your professional staff was an invited participant in the Annual Meeting of the American Academy for Cerebral Palsy, with both Dr. Robinault and Mrs. Haynes giving instructional courses and Mr. Messner, Mr. Weinrich and myself moderating roundtable discussions. The Foundation also continued to support the Academy's collaborative study on the natural history of cerebral palsy by grants to the Academy, to Columbia University and to the Meeting Street School, Providence, Rhode Island; supported the Academy's Annual Meeting by two professional grants and travel grants to UCP Clinical Fellows to participate in this meeting.

Your Medical Director spent 111 man-days in the field in calendar 1967 in visits to Affiliates, research site visits, regional workshops and participation in the International Symposium on Cerebral Palsy in Prague. He also led a teaching team to Belgrade, Yugoslavia, to share our program with colleagues in that country in its first international conference on cerebral palsy.

Dr. Robinault lectured at the University of Maine and at Boston University, as well as the Council for Exceptional Children's regional conference in Tucson and at the Annual Conference of the National Rehabilitation Association in Cleveland. In her spare time, she participated in Affiliate meetings in six Affiliate surveys and is our coordinator of the tremendous amount of data presented at the Hearings.

A special project was undertaken to develop the concept of Service packets or modules which may prove a useful tool to Affiliates undertaking shifts in program emphasis or the inauguration of new types of services. These program concepts are currently being evaluated and refined in the course of UCPA's program Hearings around the country.

There continued to be many requests for inservice training of public health personnel, including nurses and others who have special potentials and responsibilities for early case finding and these have formed a key part of the staff's time this year.

A new manual "A Developmental Approach to Case Finding", including a new wheel-type device designated to sharpen earlier detection of abnormal signs was accepted for publication by the U.S. Children's Bureau in June, 1967 and was authored by Mrs. Haynes. UCPA has distributed copies of this manual to all Affiliates. The Children's Bureau has circulated copies to all regional public health offices, all state health departments and major universities in the U.S. Demand is said to continue at an unusually high rate for so technical a publication.

With the cooperation of the School of Nursing and through the use of federal grant monies available at the University of Washington, two television tapes were made on early case finding, which have since been transferred to film suitable for use in an ordinary sixteen millimeter sound projector. Entitled respectively, "Nursing Appraisal of an Infant" and "Nursing Appraisal of Neurological Development at 3, 6 and 12 Months of Age", these films are now available from UCPA on a free loan basis and are being shown at this Conference. While these have proved useful teaching media in small classroom settings, problems of tape-film transfers hamper sound clarity for a larger audience. A federal grant has now been requested by which UCPA could make a quality film on "Early Case-Finding Techniques" and we are optimistic that favorable consideration will be given this grant request quite soon.

A great many requests continue to be received from state institutions for the mentally retarded. During the past twelve months, 17 inservice education programs were requested from institutions serving a total of 4,000 residents who also have cerebral palsy or related neurological problems. Utilizing federal grant monies to augment UCPA's travel budget, personal visits were made to conduct seminars in eleven of these institutions and two additional nurses plus four therapists were recruited to conduct programs in the six additional centers.

Using a combination of funds from UCPA, from National Association of Retarded Children and from the Federal government, our Nurse Consultant took the leadership in calling together a group of nurses to develop standards for nursing care in state institutions for the retarded. These are being tested by the American Association on Mental Deficiency in their current evaluation of such institutions and probably will be incorporated into the standards of the soon to be established Commission on Accreditation of Residential Centers.

Concern for the severely disabled individual with cerebral palsy also led to the making of another television tape, "Nursing Measures in the Care of the Child with Multiple Handicaps", which is now also available on film for loan from the University of Washington or from UCP Headquarters. Another tape on cerebral palsy suitable for basic instruction of young student nurses was made as part of the Chicago Video Nursing Project and is now available on film for loan from that resource.

Mrs. Haynes has prepared a paper on the nursing needs of the severely handicapped infants with cerebral palsy and related disorders which has now been accepted for publication by the American Journal of Nursing.

A new study of the nursing needs of individuals with cerebral palsy during pregnancy and in dealing with their first born children was started in the fall of 1967. A progress report on this was presented as part of an Instructional Course at the Annual Meeting of the American Academy for Cerebral Palsy in December, 1967. It is hoped that further study can be undertaken along these lines as there appear to be many unmet needs.

Mr. Messner has been active as a member of an interagency committee to develop a Commission on Accreditation of Residential Centers for the Retarded. It seems likely that this will become a categorical council of the Joint Commission on Accreditation in Hospitals, the first such Council under a plan recently promulgated by the Joint Commission.

He was also invited to present testimony before the National Citizens Advisory Committee on Vocational Rehabilitation which held hearings across the country. This testimony now has appeared as an article in Rehabilitation Record entitled "How the Voluntary Agency Can Help Achieve Coordinated Services for the Handicapped."

With the aid of a Small Grant from UCP's Research Foundation to New York University's School of Social Work, a graduate student has been assigned to the National Office for interne training under Mr. Weinrich's skillful supervision. She and Mr. Weinrich have worked with several Affiliates in assisting the solutions in the problems of community organization. It is believed that this represents a "first" in this type of professional education.

Another in a series of Long Term Care Workshops was held last June for Affiliates in the New England and Eastern Regions. This was attended by a sizeable group of volunteers, staff and professional advisors.

The special task force on equipment and apparatus in cerebral palsy programs has completed its charge with review of over 200 pieces. Under the editorial supervision of Dr. Robinault, the first section of the manual has been submitted to a publisher for cost analysis. We remain hopeful that a major portion of its publication cost may be borne by an outside source so that it can be widely distributed at a very low figure.

The first volume in the revised Realistic Education Planning Series on preschool planning appeared during the year and the second on psychological evaluation is ready for the printers. The Clinical Advisory Committee and staff participated in a revision of the American Public Health Association's booklet "Services for Children with Cerebral Palsy" and continually updated reference lists on research, prevocational and vocational information and colleges for the handicapped were regularly distributed throughout the year.

## VI. Report of UCP's Research Program:

You are familiar with the new focus for the Foundation's research program. After careful study of research needs in the field and the increasing program of the National Institutes of Health, the Research Steering Committee recommended to the Directors that the Foundation, henceforth, concentrate its efforts in a narrower field and in considerably more depth than in the past. I refer to the stimulation and support of studies having relevance to causative factors in brain dysfunction. This means research into how we can prevent cerebral palsy from occurring in your grandchildren and their successors.

Four areas were pinpointed for emphasis: (1) prematurity or children with low birth weight; (2) neurotropic virus, such as German measles; (3) blood type incompatibility and (4) the clinical management of prenatal care, labor, delivery and resuscitation of the newborn. We anticipate that the new program will be developed using task forces to study the current research situation in each of the major areas, ascertain what funding is needed and how teams of investigators can better coordinate their efforts and recommend to the Foundation's Board of Directors specific programs and investigators which should be supported. We also feel that the Foundation will be receptive to proffered applications for grants within the framework of the new program.

In prematurity of children with low birth weight a number of exciting things are happening. The Collaborative Study of the National Institutes for Neurological Diseases and Blindness has shown a considerable difference in intelligence test scores between children prematurely born and those who were full term. IQ scores were 10-12 points lower in the small prematures than in full term infants as well as in the comparison between white and non-white. Twenty-five per cent of the smallest white prematures had IQ scores below 80 as did 37.5% of the smallest non-white.

Interesting results were obtained when test scores were related to the educational level of the mother. There was a 37 point spread in mean IQ score (90-117) between children of mothers with less than seven years of school and mothers who were college educated. Among Negro children of the same birth weight group the spread was 78 to 102.

These data presented at the First International Conference on Prematurity in Florida in January also pointed out the fact that causes of intrauterine growth retardation probably relate to insufficiency of the maternal organism rather than to abnormality of the placenta.

At Yale University, with UCP support, Dr. Edward J. Quilligan is attempting to understand the various receptor mechanisms which are responsible for changes in the fetal heart rate at various stages of gestation. Using the fetal lamb as an experimental animal, he is attempting different types of perfusion techniques on the fetus in order to attempt to separate out the effects of lowered oxygen to the mother and increased carbon dioxide in her blood. A corollary of this effort is the attempt to determine the effects on the brain of varying periods of oxygen lack by perfusing the brains which have normal oxygen tension, normal carbon dioxide tension and a normal blood pH. These studies are throwing insight into the mechanisms for controlling fetal heart rate and, of course, oxygenation of the central nervous system. While the time sequence of changes within the brain has been clearly elucidated in the fetus without oxygen by a former UCP grantee, Dr. William F. Windle, similar time sequence patterns must be investigated, in the animal with oxygen lack, in order to determine and compare the two preparations. Since oxygen has been accorded a major factor in the etiology of brain damage when there are insufficient amounts to clearly supply the fetus, it is important for such studies as these to be funded in order to develop methods for provision of adequate oxygenation during periods of resuscitation and danger to newborn infants.

A corollary of this problem is determining the various mechanisms which regulate the growth of the placenta through which the fetus's nutrition and oxygen are supplied during his period of gestation. At high altitudes, near Denver, the Foundation's grant to Dr. Giacomo Meschia, University of Colorado, is enabling him to study pregnant sheep and monkeys using chronic fetal catherization and comparing the results of the studies on animals living at low altitudes. This research will make it possible to confirm mechanisms of adaptation by the fetus and the placenta to maternal oxygen lack by comparing the fetal oxygenation and maternal oxygen pressure at high and low level altitudes. Careful record is made of the oxygen and carbon dioxide content by gas chromatography, glucose content of the blood and appropriate blood studies including red cell counts, hemoglobin determinations, etc.

In addition to the Foundation's early support to Harvard's School of Public Health for initial studies on the German measles virus by Nobel Laureate Thomas H. Weller and Franklin A. Neva in the determination of the characteristics of the virus, its grant to New York University this year is enabling Dr. Saul Krugman and Dr. Louis Z. Cooper to continue their studies on the natural history of rubella acquired in utero or acquired after birth. These investigators are also developing and evaluating new virus isolation and serological techniques and will, therefore, be able to evaluate the efficacy of human antirubella immunoglobulin and newly develop vaccines against rubella. Basic information concerning the epidemiology, clinical course, virus-excretion patterns and neutralizing antibody response to German measles infection in childhood has been accumulated by these investigators in research at the Willowbrook State School, Staten Island, New York. The Foundation's grant will also permit similar studies in a group of more than 200 infants with congenital rubella acquired during the 1964-65 epidemic. Such studies will considerably expedite virological research in the area to speed the development of a safe effective vaccine to protect all teen-age girls of the future against the acquisition of German measles early in pregnancy with the high risk of a deformed infant.

One problem of concern is the shedding of live German measles virus from the throats of those in whom the experimental vaccine is injected. While the vaccine produces antibody and, therefore, immunization, in those to whom it is given, the shedding lasts several days. However, NIH studies involving approximately 500 vaccines and 500 susceptible contacts have shown no evidence of communicability.

At the present time, there is intensive work underway to determine if the lack of transmissibility can be relied on as being safe for general use, and whether or not the administration of the live vaccine can be accomplished in women of child bearing age, where pregnancy must be considered.

Through the gentle but persistent stimulus of Mrs. Goldenson, we have established what may be a very productive relationship with the Technology Utilization Program of the National Aeronautics and Space Administration. Mrs. Goldenson, Mrs. Hausman, Mr. Cunerd and I met with officials of the National Aeronautics and Space Administration in Washington to explore such possibilities with James Webb, NASA's Administrator, from this came a meeting with NASA's scientists last week by a group of UCP clinical and service advisers. With NASA's help, the Aerojet Laboratories have developed a "lunar walker" or unmanned, radio-directed instrument carrier, which can be adapted as a prototype of a wheelless walker for handicapped children. This is an eight-legged vehicle, which keeps four legs on the ground at all times, moves with stepping motions and is able to walk across rough or sandy terrain, climb stairs, clear curbs, etc., which would balk an ordinary wheelchair. Its sole control is an upright stick, which can be modified with a chin cup, to serve children who cannot use either arms or legs and must steer the vehicle with their heads. Dr. Lee Arnold, Professor of Aeronautics at New York University, and your Medical Director will negotiate modification of this equipment with the industrial developers for use on an experimental basis with cerebral palsied children and adults.

In the biomedical area, NASA's investigators have developed a "sight switch" which can be activated by voluntary movements of the eyes. It has been used as a potential aid to astronauts in situations where high-G forces might make them unable to move their arms or legs. The device consists of light sources mounted at each side of a pair of eyeglasses which bounce a light into the wearer's eyes and detect the difference between the reflection from the white and darker pupils. Whenever the pupil of an eye moves across the path of the light beam, the reduced reflection activates an electric switch. The sight switch, properly relayed, can be put to a variety of uses to assist a patient who cannot move arms or legs. For example, the sight switch has already been adapted to a motorized wheelchair that enables a paraplegic patient to control the chair solely with his eyes.

For several years, NASA's Jet Propulsion Laboratory has been using digital computers to enhance the clarity of photographs televised from spacecraft. The computer in this process has been likened to a high-fidelity phonograph, which can be made to emphasize bass or treble sounds to suit the listener's taste. These techniques have now been used to enhance the clarification of medical X-ray films to get sharper views of details that might be lost in the original.

At our joint meeting last week with the NASA investigators, our discussion centered on these developments with such potential for cerebral palsied children, together with (1) predicting the effects of weightlessness on the pregnant animal when one is sent into space; (2) the use of sensory prostheses to enhance proprioceptive senses in hemiplegic patients; (3) the development of polymer plastics for use in braces for strength, lightness and lower cost; (4) use of computer assisted instruction for severely involved cerebral palsied students with normal or superior intelligence quotients; (5) smaller power packs for wheelchairs; (6) voice amplifiers and clarifiers for athetoid patients, etc.

The group concluded that there is a real need for physicians and related professional workers in the field of cerebral palsy to interest themselves in biomedical application of engineering research, to be specific in indicating needs to scientists in nonmedical research disciplines and that more effective ways of handling and coordinating the mountains of data from our research and clinical laboratories are being slowly developed for more rapid clinical application.

For the past four years, your Foundation has been supporting the evolving program of special education at the University of Cincinnati as a result of its early interest in helping academic programs in special education get started. As a result of the Foundation's decreasing term grant of $25,000 over a five year period, which expired in December 1967, several significant things occurred at that university which demonstrate the wisdom of the Foundation in providing seed money for research and training programs:

1. The present program in special education has gained departmental status;

2. Its students now number:

   (a) 250 full-time undergraduates;
   (b) 350 part-time graduate students;
   (c) 20 full-time graduate students;

3. The Special Education Department has seven full-time faculty members and utilizes the services of 20 other professionals on a part-time basis;

4. It provides course offerings in every area of special education and provides total teacher education programs in several;

5. Its present plans for the expansion call for six additional full-time faculty for the fall term this year.

Dr. Zemanek, Chairman, of the Department, wrote me last week to say that this mature program in the behavioral sciences could not have been accomplished without UCP support and faith. Our grant helped to focus the attention of the University administration on special education and its value in educating handicapped children as well as markedly increased community interest and support.

UCP's Foundation had two firsts during the year -- it appropriated over $890,000 for research and training, the largest yearly total in its history and its total appropriation since UCP's inception in 1949 exceeded $10,000,000 an impressive record particularly for a voluntary health agency whose primary objective is service and education.

Here, then, are only highlights of your professional program activities and accomplishments at National this past year. On your behalf, I want to pay warm tribute to our staff -- to Woody Messner, whose keen and perceptive sense of community organization of services has made him a respected and sought-after leader in our field; to Isabel Robinault whose coordination of our many faceted activities in this department has been gentle, yet firm, and most effective; to Ernest Weinrich, whose insistence that UCP pioneer in stimulating wider use of social workers for cerebral palsied individuals and their families and his persuasive and empathetic leadership in programming for young adults who cannot work competitively have had important rammifications in changing our service philosophy and I salute him for it; to Una Haynes, our knowledgeable, spectacular and most gracious image in this field. To these and to our indefatiguable secretarial staff, I extend my sincere thanks.

VII. Conclusion:

As we consider the next year with new program emphases and methods of achieving our individual and organizational objectives, we must look beyond the experience of Charlie Brown, our youthful philosopher. You may recall Charlie Brown's admonition to his baseball team, "You know what our team lacked last year? It lacked organization! Well, this year it's going to be different! I have written down the name of each player and what position he plays and I've attached the paper to a clipboard -- and if that isn't organization, I don't know what it is!"

What, then, is our essential role as we rededicate ourselves for our task this next year, Mr. Harold B. Miner, former U.S. Ambassador to Lebanon, put it succinctly, when he said that the future for us "depends on the intrinsic nature of our internal society -- what we are, rather than what we profess to be. The world will follow and respect an America purposeful, united, moral and true to its great traditions, but it will do neither for an America divided, decaying at its roots, irresolute and unable to put its house in order." We, in United Cerebral Palsy, are an important part of our American society and the work we do for those less fortunate than ourselves helps to restore the saneness to our way of life wherein people love people and use things, for far too often around us people are using people and worshipping things.

In a world that may perish from hunger by 1975 as many food scientists tell us, in a time when a single irresponsible man can press a button and destroy civilization, in an America gingerly treading the edge of a civil war fought not between Blue and Gray but Black and White, by guardsman against guerrilla, each of us has a personal responsibility to help in a noble effort by our active participation and concern. For causes such as United Cerebral Palsy are the hope of our sick world and each must make his very best contribution if, at the end, each of us can say -- I was not a bystander, but I participate and, because I did, good things happened to others. "Let us do it now, let us not defer nor neglect it, for we shall not pass this way again!"

"Ah, friends, dear friends, as years go on
And heads get gray, how fast the guests do go!
Touch hands, touch hands with those that stay.
Strong hands to weak, old hands to young,
--- the circle round, touch hands.

The false forget, the foe forgive, for every guest will go,
And every fire burn low and cabin empty stand.
Forget, forgive, for who may say that today, or any day
May ever come to host or guest again.

Touch hands!" *

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*John Norton's Vagabond by William Henry Harrison Murray